

**SECONDARY STIGMA: A CASE STUDY OF PEOPLE  
AFFECTED BY HIV/AIDS IN WHITE CITY JABAVU –  
SOWETO**

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requirements of the degree of Master of Arts – Sociology of Health and  
Illness**

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## **ABSTRACT**

This qualitative research study is about the lived experiences of people affected by HIV/AIDS related secondary stigma in White City, Jabavu – Soweto in South Africa. Whilst the initial project was fairly narrowly conceived, the findings from this research drove the researcher to explore, at some considerable length, two principal areas which were not part of the original conception of the project. These two areas are:

Firstly, the researcher's argument that stigma in White City must be understood in the broader context of pre-existing forms of stigma which he asserts create a "stigmatizing environment" in which new forms of stigma find a fertile social, cultural and economic world in which to take root and flourish.

Secondly, the researcher's recognition that the manner in which the research participants develop coping mechanisms to deal with their experiences of secondary stigma is a critically important dynamic in understanding the experiences of stigma among those research participants.

## DECLARATION

I declare that this thesis is my own unaided work. It is submitted in partial fulfillment of the degree of Master of Arts at the University of the Witwatersrand, Johannesburg. It has never been submitted before for any degree or examination in any other university.

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Caswell Motlejoa Matima (JR)

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## **DEDICATION**

This endearment is dedicated to my late father Caswell “Bra Cas” Motlejoa Matima (Snr) who was born in downtown Johannesburg, at the intersection of Von Weiligh and Albert Streets but grew up in house number 2257 Hlake Street, Western Native Township - I wish you were physically here to witness my achievements but I know that spiritually you are watching and are happy for me AND also to my mother Adelaide Alita Khothatso Matima who is the source of my inspiration and support. She was also born in downtown Johannesburg at the intersection of Commissioner and Bezuidenhout Streets but grew up in house number 32 Gerty Street, Sophiatown.

AND

To all those people infected and affected by HIV/AIDS across the globe.

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## **LIST OF ACRONYMS**

AIDS – Acquired Immune Deficiency Syndrome

ANC – African National Congress

ART – Antiretroviral Treatment

ARV's – Antiretrovirals

BCM – Black Consciousness Movement

CBO – Community Based Organization

GEAR – Growth Employment and Redistribution

HIV – Human Immuno-Virus

NGO – Non-Governmental Organization

PAC – Pan Africanist Congress

PLHA'S – People Living with AIDS

PUTCO – Public Utility Transport Corporation

TAC – Treatment Action Campaign

TB - Tuberculosis

# **CHAPTER 1**

## **INTRODUCTION**

## **1.1. INTRODUCTION**

The aim of this study is to look at how secondary stigma, also known as courtesy stigma, affects people and families as a result of their association with someone infected with HIV/AIDS. Their stories and experiences matter especially because they are first-hand witnesses who are touched by the stigma and consequently the knowledge they share can help comfort other individuals and families undergoing the same experience, as well as give them an insight and understanding of how to handle their dilemma. What follows is a discussion of the history of White City whose purpose is to highlight the pre-existing culture of stigma in this township.

## **1.2. RESEARCH QUESTION**

The following is my research question:

“What is the nature of HIV/AIDS Secondary Stigma in White City, Jabavu”?

In order to draw a sharp focus and the parameters on this research topic, the following subsidiary questions will be asked.

- What are the socio-economic conditions of White City?
- What has been said about AIDS stigma?
- What are the dynamics of stigma amongst the people of White City?
- What are the experiences of secondary stigma amongst people affected by HIV/AIDS?
- What is the impact of secondary stigma amongst individuals affected by HIV/AIDS in White City?
- What are the coping strategies of individuals affected by HIV/AIDS?

### 1.3. BACKGROUND TO THE CASE STUDY: White City, Jabavu – Soweto

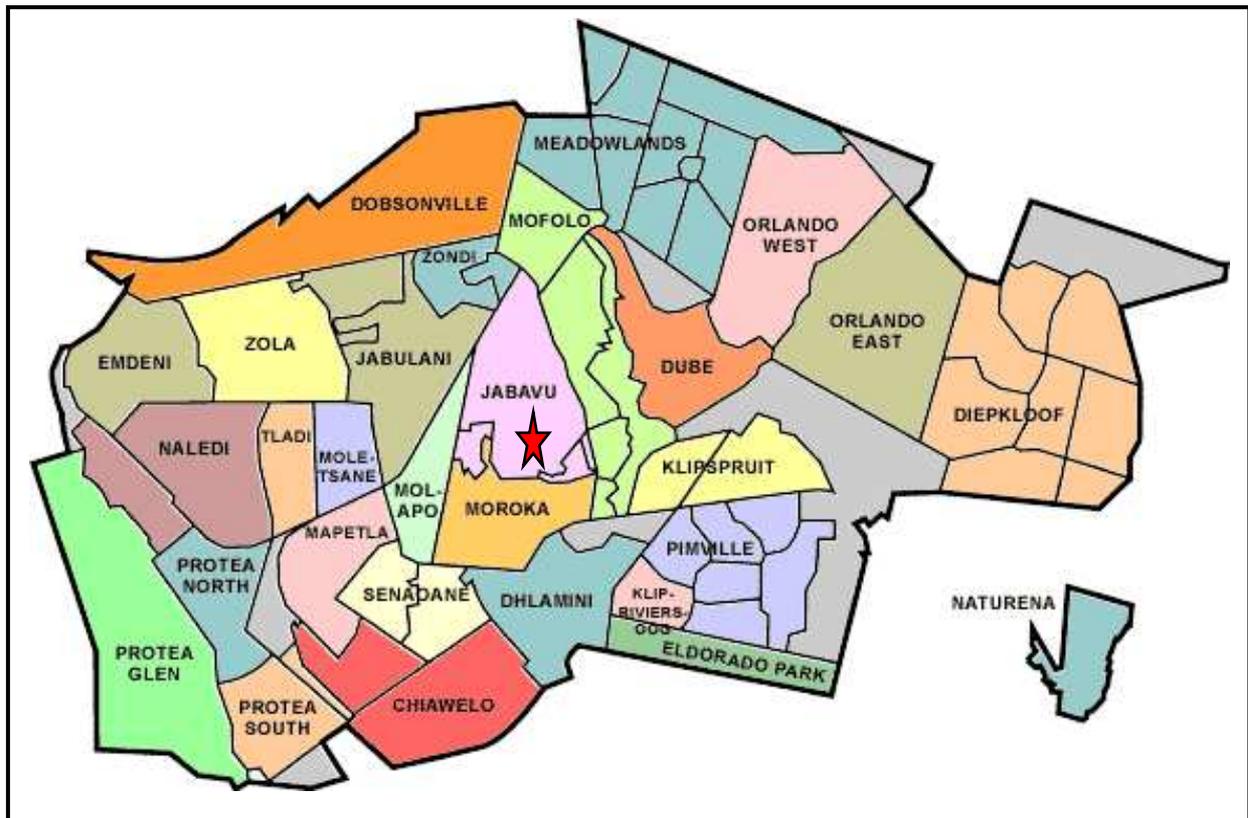


Figure 1: A map of Soweto. (Available at [www.sahistory.org.za](http://www.sahistory.org.za) [accessed 03rd/12/2009])

**Note:** (The discussion that follows is partly based on my knowledge as a resident of Soweto supplemented by some literature).

#### A. GENERAL BACKGROUND

Discussing White City without mentioning a brief history of the city of Johannesburg is like having a conversation about Alaska or Greenland without mentioning Eskimos.

The discovery of gold in 1886 spurred massive migrations of people from the rural countryside and neighbouring states into Johannesburg, in search of employment and greener pastures. As Morris (1980: 7) explains:

Following the discovery of gold in 1886, large numbers of people streamed into Johannesburg, at the time little more than a temporary mining camp. The first census in 1896 revealed a population of 102 000, of which approximately half were Black. Since that date, the proportion of Blacks to the total population has increased substantially.

Legislation passed such as the 'hut tax of 1890' meant to boost the declining coffers of the Cape colony under British rule, as well as the '1913 Land Act' which dispossessed Africans of their traditional ancestral lands, also played a major role in the mass migrations that occurred from the countryside into Johannesburg and other cities.

At first, human settlements in Johannesburg were multiracial slums. However, some White families who could afford lived separately in wealthier suburbs. The influx of more Black people into the city from the rural areas created serious social problems such as overcrowding, high levels of unemployment, the high crime rate and the squalid conditions in these slum areas worried the authorities given the racially conscious history of South Africa. Apart from the migrant mine workers who lived in single sex mine hostels or compounds, there were other migrant workers who were employed to do domestic work whilst others worked as assistants in the emerging secondary industries, office blocks and shopping complexes. Many of these people were housed in the back cottages and back rooms of their mostly White employers who lived in the city centre. Given the racial history of South Africa and the policy of separate development, this did not go down well with the authorities and they made a plan to move all Black people into their own residential areas that would act as labour reserves for the big towns and cities.

Sakar (2007:188) observes:

The story of the notorious apartheid citadel of Soweto, and its experience of segregation, was, of course, very different from the postcolonial Indian experience, but there were also similarities. Soweto went back to efforts, starting in the 1920s, to break up the proximity between prosperous European residential areas in Johannesburg, and slums that initially housed a very mixed population, including poor whites. An inter-racial 'Marabi' culture had briefly flourished there, and was felt to be a threat to dominant groups. The origins of apartheid in the other urban areas lay, in part, in projects for slum-clearance, pushing the poor – who in South Africa were predominantly black – away from the central districts, initially on grounds of sanitation, urban development, and, no doubt, beautification. It was through such displacements, progressively more brutal, that Orlando emerged in the 1930s, fifteen kilometres away from Johannesburg – the nucleus of what developed into Soweto.

However, the first township of Soweto was Klipspruit dating back to around 1904, followed by Orlando dating back to October 1931. At that stage the name Soweto did not exist and it is

only in 1963 when a whole cluster of townships had developed that the name Soweto was adopted after four years of competition for a suitable name.

The section of Jabavu called White City came into being between 1947 and 1960 when the government launched a massive campaign to demolish squatter camps or emergency camps that were often, filthy, disease prone and overcrowded. Residents of the Moroka and Jabavu emergency camps were relocated into the new townships of White City, Jabulani, Moletsane, Naledi, Senaoane and Dlamini. These townships were collectively called the 'wild west' by residents from other Soweto townships because the former were very impoverished and in the 1960's and 1970's they experienced a very high crime rate.

White city, marked with a star on the map above, is situated in central Soweto about 20 kilometers south –west of Johannesburg and is one of the two townships that are collectively known as Jabavu. The other township is simply known as Central Western Jabavu or referred to by the locals as CWJ. Soweto itself is an acronym for South Western Townships which is made up of about 30 townships.

To the north-east Jabavu is bordered by Mofolo another Soweto township, to the north-west it is bordered by Zondi and Jabulani townships and stretching from the south-eastern side to the south-western side it is bordered by Moroka and Molapo townships.

Jabavu is named after John Tengo Jabavu (1859 – 1921), a teacher, preacher, editor and champion of the rights of African people in South Africa, who originated from the Eastern Cape.

Soweto residents generally refer to White City as 'Kansas City' because of its above-average crime levels and socio-economic similarity to a ghetto area found in Kansas City, in the United States of America. In explaining why this township was called White City as well as the unfavourable socio-economic conditions there, Bonner and Segal (1998: 130) state that:

White City – given its name because of the concrete roofed 'elephant houses' which were originally painted white - is the more densely populated suburb in Soweto and housed the lowest income group. On average, more than four families shared a yard in this crime-ridden area.

However, other people interviewed indicated that over and above the white colour of the houses, the name White City may have also been entrenched when pioneer inhabitants were

moved into these solid brick houses from the deplorable tin shacks they used to occupy as shelter and other envious shack dwellers left behind inferred that the newly built brick houses were like the White man's suburbs and thus the new occupants were now like White people in terms of their better living conditions. That may also be true considering that when the apartheid authorities started building White City and other formal houses in Soweto, Mr James Sofasonke Mpanza, credited by many people as the founder of Soweto and the Sofasonke Party whose popular slogan was 'Housing and Shelter for All' made the following statement:

Mpanza told a meeting of subtenants that the half-built structures were to be given to people from black areas the government wished to turn into 'whites only' suburbs and not those living in appalling conditions within Orlando itself. He also pointed out that the Council planned to increase the rent for these houses which would place them beyond the reach of most ordinary people (Bonner and Segal 1998: 25).

Mr Mpanza arrived in Orlando in 1934 and some people describe him as a very intelligent person who cared a lot about the plight of the poor. Bonner and Segal (1998: 20) cite one observer who described Mr Mpanza this way:

Mpanza was described by one observer as a 'fighter, lover of race horses, fluent in English, educated, keen on soccer, popular with women, astute and experienced with law, a persuasive preacher and a jack of many other trades'.

Nowadays Soweto is commonly and intimately referred to as *Msawawa* which is a nickname simply without any specific meaning except being used as an expression of endearment by its residents. This name has been popularized because even other people from outside Soweto across South Africa and Southern Africa now quite often use that name.

Unlike in other Soweto townships where houses are mostly the four roomed structures with zinc or asbestos roofs, cynically called 'matchbox' houses by residents, houses in White City are semi-clusters comprising of a single free-standing structure that is divided into three sections, housing three families occupying either two or three rooms and each with its own small yard. African people are known to live in larger families, be they of the nuclear or extended type and as a result there is overcrowding in these two rooms and three rooms. Each common physical address is differentiated by a different alphabet, for example house number 22A, 22b and 22C and so on. The roofs of the houses are made of concrete instead of the usual zinc and tiles as in other townships. The only other township in Soweto with houses

similar in structure and paint is Mzimhlophe, Ezindlovini section, which is a Zulu expression for place of the elephants. The similarity is also suggested by the name because Mzimhlophe means White City in the Zulu and other Nguni languages. Even the houses are called smarties (colourful sweets) due to the similarities in the two townships' colourful paintwork of pink, bright green, cream white, light blue and so on and yet Mzimhlophe does not have a reputation as bad as that of White City in terms of the perceptions projected by other residents of Soweto.

White City has its fair share of famous landmarks such as Morris Isaacson High School, along Mphuti Road, which was the epicenter of the June 1976 student uprisings against the compulsory use of Afrikaans as an official medium of instruction at schools, Bantu education and the system of apartheid. (Farouk, 2006) At the intersection of Phera Street and Khumalo Street not far from the well known cross roads junction linking Mofolo and White City, there is also the famous St. Paul's Anglican church, which also serves as a highly valued community centre as it houses several health promoting and development oriented non-governmental organizations (NGO's), as well as the American built and sponsored Rosa Parks library, so named after the African-American lady who defied racism and refused to give her seat to a white man in a bus in America.

The township's administrative offices are situated along the corner of Phera Street and Mlangeni Street and among other things they also serve as a pay-point for the monthly rent paid by residents. As in the whole of Soweto, all roads are tarred in White City, all formal houses are electrified, households have water directly to the property and households are serviced by formal waterborne reticulation. Among other amenities the township boasts of a community swimming pool, an old-age home and the Adelaide Tambo school for the mentally and physically challenged.

Even though there are some signs of decline, unemployment in South Africa is said to be still very high and White City has its own share of the unemployed. Residents of White City come up with innovative income generating ideas such as offering entertainment by turning their homes into shebeens or taverns selling alcohol.

A report by 'The Mail and Guardian Newspaper' online reported on the 29<sup>th</sup>/10/2009 that:

South Africa's official jobless rate increased to 24,5% of the labour force in the third quarter of 2009, from 23,6% in the second quarter, while the labour force fell sharply, a report showed on Thursday (The Mail and Guardian, 2009).

In White City both the young men and women strategically set up their own car-wash spots targeting mostly shebeen patrons and other bypassing motorists. Businesses nowadays operate in a deliberate symbiotic relationship because nearby these car-wash parks, as they call them, there is usually a butcher also with outdoor braai facilities. People and motorists buy meat and pap (a South African maize staple) and then braai the meat and eat their food whilst awaiting their cars having a good wash and detailed polishing.

Many youth with a standard ten and others with tertiary qualifications are also unemployed. A lot of adults are also unemployed and the situation is worsened by the current world economic recession that has caused many multinational companies to retrench a lot of their employees as a result of restructuring geared towards cost saving.

I, the researcher, have many friends and relatives who live in White City, Jabavu. Some of these friends are ex-schoolmates and others are childhood friends who used to live in Dube, another township in Soweto where we grew up but in their case their families relocated to White City for a number of reasons and yet we still keep contact. Now firstly, on numerous visits to White City, to see both family and friends, I realized that there were more funerals in one weekend than there is in my section of Soweto.

Secondly, I also realized that in the weekly 'Community News' and 'Funeral Notices' section of 'The Sowetan Newspaper,' it seemed an anomaly that so many young men and women are announced as deceased, mostly from non-accidental or violent deaths. This could only mean that many of the deceased died from sickness or from other natural causes which is an unusual occurrence as this never used to happen before.

On probing further, I learnt that most of these deceased are the youth, mostly girls, between the ages of 25 and 34 years. I realized that there is a need to find out more about the reasons for the escalation in the number of deaths and contacted 'The Sowetan Newspaper,' local Soweto clinics, Chris-Hani Baragwanath Hospital, Tarra Hospital, South Rand Hospital and Helen Joseph Hospital in Auckland Park who generally pointed towards the direction of

HIV/AIDS and its high prevalence levels despite programmatic efforts by the government. In one month I was shocked to realize that, in White City-Jabavu, one family experienced tragedy as two sisters died one after the other and they were buried on consecutive weekends. These burials often overstretch the already meager budgets of these families who in most cases depend on one member who carries the burden as the breadwinner due to the high unemployment rate. I also realized that whenever people refer to these families they use derogatory terms and in turn it would seem that surviving members of these families are socially withdrawn as compared to their previous outgoing nature. Some members of these families used to be valued highly in their communities because they participated vigorously in communal events such as in preparations for the weddings of the young in their neighbourhoods and in other traditional and cultural events occurring within the community. They were instrumental in many community related projects and yet their participation is now withdrawn and they seem to be isolated.

## **B. DYNAMICS OF STIGMA IN WHITE CITY**

In Soweto there is a general stigmatization of White City residents and as a result White City is the least desirable township in Soweto. This is structural and historical as the root causes can be traced back to the policy of apartheid and its resultant social inequalities evident in the type of 'inferior' housing, the high rate of violent crime as well as the higher levels of unemployment and poverty in that township. This general perception about White City extends to a perception that the young ladies from White City lack class and therefore, to fall in love with a young lady from that area is tantamount to a scandal amongst one's family members, friends and other close associates. Young men from White City are also not viewed favourably by many people and suspicion always surrounded them. For instance, the general attitude at schools around Soweto when another student's books or other valuable item went missing in class was to search in the direction of students who come from White City. Their poverty stricken backgrounds made them scapegoats by other students keen on labeling them as thieves and delinquents. Their general lack of resources, including full school uniform, text books and pocket money further compounded perceptions about them as potential school drop-outs, delinquents and perpetrators of other socially unacceptable behaviours.

Furthermore, in the 1950's, 1960's and the 1970's there was a saying that 'White City is not a place for sissies, which is a category of people who were generally stigmatized as being

physically inferior and hence you had to be very tough to survive there. The men were tough and many young men belonged to gangs who often fought over issues around territory or over the spoils of crime. The ladies were also very tough and one had to be very careful when in a love relationship with a lady from White City because if you crossed the line and made her angry, she could beat the daylights out of you. Therefore, a tough man was highly regarded and valued as a shelter for protection contrary to men who preferred communication over fighting. The latter kind of a man was disparagingly referred to as a loudmouthed sissy or softie and was not highly regarded by many people.

Sub-cultures emerged which manifested themselves in the style of dress and sense of fashion determining whether you were a 'moegoe', a 'sissie' or a 'clever'. Generally, three fashion styles owing allegiance to a particular fashion group could be distinguished. These were the Hippies, the Ivies and the Pantsulas.

The 'Hippies' belonged to a fun and peace loving fashion group which wore tight fitting bell bottom trousers matched by tight fitting muscle tops. The 'Ivy' fashion style was turn-upless three quarter length trousers that did not cover ankles and exposed socks made of silk fabric, which was some sort of their trademark. On the other hand the 'Pantsulas' are another fashion group which regarded itself as tough, streetwise and wore loose fitting trousers with a turn-up made of thick linen fabric such as 'Dobshire' and 'Brentwood' with their matching viella shirts and matching shoes such as Saxon, Florsheim, Blutcher and the others .

In an interview with Bonner and Segal (1998: 60), Sibongile Mkhabela, a long time Soweto resident and political activist, summarized these fashion sub-cultures this way:

Each male style had its lady counterpart. You had the tsotsis and the ladies who went along with them were called the caberesh – a very denigratory name. The caberesh later became the emshoza and the emshoza would later go along with the Pantsulas. It was the Ivy lady with the Ivy gentleman. They would all wear nice dignified clothes. They would dress more sporty or smart casual. Then there would be the real ladies who would dress very formally. These were the trends. Mkhabela also remembers the exceptionally high heels worn by young women, and the lengths they would go to to wear the fashionable hairstyles of the day.

Each group was identifiable by its own type of subculture extending beyond fashion and included aspects such as the type of entertainment, the favourite shebeen as a hangout place,

the favourite type of beer and alcoholic beverages preferred, the type of woman one gets attracted to, the type of girlfriend one keeps, the dance style and so on.

Furthermore, the 50's, 60's and the 70's thugs had a field day robbing scared pedestrians enroute to their homes in the area as well as those going to the neighbouring townships. '*Poho*' (Sesotho), '*inkunzi*' (Nguni), '*bul*' (Afrikaans) and 'oxen' (English) are all euphemisms referring to the strength and forceful nature of a male cow to fight for its place in a herd and were commonly used by the residents and thugs to denote armed robbery. Individuals walking through the streets of White City after sunset and in the early hours of the morning before sunrise risked being robbed mainly at knifepoint and sometimes at gunpoint by marauding bands of thugs who were after their money and other material possessions such as groceries and clothes worn by the victim. Payday was the worst nightmare for workers who relied on public transport as these thugs could easily spot a potential victim from a distance as he or she stepped out of a public transport like a Putco bus at the then notorious crossed roads intersection. Bonner and Segal (1998: 65) report that:

The 1960's and early 1970's also witnessed the birth of a new generation of tsotsis who became an increasingly conspicuous feature of Soweto life. Despite the reputation of thuggery, intimidation and vandalism usually associated with these bands of youths, gangs often started innocently enough as a way of simply passing time.

Even motorists were not safe as there are many stories told about thugs who way laid motorists and their passengers as they stopped to observe the then four-way stop sign at crossroads. Motorists were urged to keep all car doors locked as they drove through White City. Some daring thugs were not afraid to open unlocked doors of a passerby's car, force the occupants of the vehicle out, with the aim of robbing them of their money and other valuable possessions. In those days cars were not hijacked after the passengers were robbed which is a different phenomenon from nowadays whereby car hijacking rackets carried out by organized crime syndicates are a multi-million rand business with a market in South Africa and in the neighbouring states. Hijackers clone these vehicles often with the help of corrupt policemen and corrupt officials in the vehicle licensing department.

Nevertheless, White City has a place in the historical annals of the anti-apartheid liberation struggle. During the anti-apartheid struggle heroic scenes were enacted as the local residents waged fierce resistance against the then South African Police (SAP) and the then South

African Defence Force (SADF) which were deployed in Soweto to quell the 1976 students' uprisings against the unjust system of apartheid. Apparently some police and army units were very reluctant to be deployed there to maintain the then so-called 'Law and Order' because of the imminent danger as a result of the fierce and unrelenting resistance waged by the residents.

It would not be far-fetched and it can only be natural to assume that there are many good people of outstanding moral character in White City and yet these people's voices are not heard as a result of the stereotypes and perceptions of other people about their township. It would seem that there are historical pre-existing forms of stigma associated with this area and are compounded by the latest additional forms of stigma elicited by the advent and prevalence of HIV/AIDS. What we have here is an enabling environment in which stigma operates at many levels. Secondary stigma seems to thrive where there are perceptions and a culture of stigma like it is the case in White City.

As we will see in the literature review chapter, the historical impact of contextual structural issues is not explored extensively enough, to help unmask their contribution in creating a stigmatizing environment in this township. For instance in the case of White City the historical state sponsored violence of the past apartheid government has had a profound effect on the lives of the residents. Therefore in grappling with the causes of HIV/AIDS related secondary stigma in White City, one has to dig deeper and look at other pre-existing layers of stigma within which this secondary stigma exists. In other words the existence and intensity of HIV/AIDS secondary stigma cannot be viewed in isolation but must be understood within a historical context of the development of the township whereby other layers of stigma such as the type of housing, perennial poverty and unemployment, crime and gangsterism have been in existence for generations upon generations.

## **HOUSING STRUCTURES AS A SOURCE OF STIGMA**

As mentioned previously people living in White City have always been looked down upon and despised by other residents of greater Soweto. One of the reasons for that was the small structure of their three roomed houses comprising of a relatively small kitchen, small dining room and a small bedroom which in many instances could not even accommodate a double

bed. Indeed these houses have a very small living space to accommodate sometimes large families of up to ten and fifteen people.

Bonner and Segal (1998: 24) explain that in trying to contain the influence of James Mpanza as well as alleviate the problem of the sprawling squatter camps around Soweto, the Johannesburg City Council responded this way:

To meet the challenge, the Council hastily devised a plan to provide temporary accommodation, rows of breeze-block shelters of ash, sand and cement were erected in the new area of Jabavu. Roofed with corrugated asbestos and lacking fireplaces, chimneys and windows, these structures were 9 square metres, and stood 2.5 metres high at the back and two metres high at the front. In return for a bare minimum of services (bucket sanitation, and water and refuse removal), a monthly fee of 5 shillings (50 cents) was charged.

Looking at the trajectory of the development of White City one realizes that from its inception as an informal settlement of shack dwellings to its status as a formal residential area, the then apartheid housing authorities never meant it to be a decent and respectable township with houses big enough to house the relatively larger size of Black families. It is a point worth noting that many Black families define the concept of family beyond the western nuclear type of family and their definition of family is relative to the size of the living space that accommodates other members of the extended family such as the aged parents, the unmarried uncles and aunts, the disabled, orphans, the unemployed and other destitute or indigent members. Therefore, the planning of the formalization of the previous informal housing structures should have taken into account the cultural dynamics surrounding the African (Black) family into account. Apartheid policies never meant to grant permanent urban residential status to Black people because Blacks were only recognized as providers of cheap labour meant to service the mining and other supportive secondary industries that had emerged with the discovery of gold on the Witwatersrand during the 1880's. Workers who reached the age of retirement were expected to return to their tribal homelands in the countryside and make room for the younger, healthier and eager workers entering the market. In other words in the rush for surplus profits the welfare of Black communities, such that of White City was sacrificed and relegated to the bottom of the heap of priorities. It would seem that Dr Hendrik Verwoerd, the architect of apartheid, who also qualified in Germany as a Sociologist and a Psychologist knew the deliberate negative effects and the trauma caused by overcrowding.

This is some form of state or structural violence against its own citizens because as Farmer, Nizeye, Stulac and Keshavjee (2006: 1686) put it:

The term ‘structural violence’ is one way of describing social arrangements that put individuals and populations in harm’s way. The arrangements are *structural* because they are embedded in the political and economic organization of our social world; they are violent because they cause injury to people (typically, not those responsible for perpetuating such inequalities).

Family members fought and still fight over their own private spaces in these small three roomed dwellings. Adults and children were not privy from each others’ activities especially the parents and couples who had to perform their conjugal sexual activities with the utmost care and swiftness to avoid the embarrassment of being discovered by young children and other members of the family. In their book entitled: Soweto – A History. Bonner and Segal (1998: 24) capture the opinions of Ethel Leisa and Jane Khanyeza whose families were among the first to move out of the squatter camps into the new Jabavu housing structures. First Ethel Leisa explains their plight this way:

Rooms were quite small, but those rooms were meant to accommodate a family. In the morning when we got up, it was so difficult. For instance, the father of the family had to prepare to get to work while his children were still asleep. There was no bathroom; there was no other room. He had to get out of bed and bite the end of the blanket with his teeth to cover his front part and then put his legs into his trousers. There was not any other way of having privacy except to use that blanket. (Ethel Leisa)

Jane Khanyeza further described the conditions as a result of overcrowding in these small houses this way:

When we went to sleep, Jane Khanyeza continues, there were so many of us. It was my brother, my father, my mother, my sister and me and the other children, the smaller children. We slept under the table. My mother and father got the bed.

Explaining the apartheid government’s violent role in the Soweto rent boycotts of the mid 1980’s and the consequent policy of evictions for rent defaulters, Bonner and Segal (1998: 130) state that:

The ‘White City War’ began on the night of 27 August. The police burst in on a meeting that had been called to discuss the issue of evictions. A few people in the crowd were chanting, ‘We are not fighting’, and were reported to be holding their hands in peace. Without warning, the police opened fire, killing 21 people and injuring 98. Following the carnage, the Council beat a hasty retreat and their housing

director, Del Kevan, stated that it was now 'too provocative to carry out evictions when there is such trouble in the townships'.

Therefore, apartheid and its housing policies for Black people served to rob families of their dignity, self-worth and peaceful co-existence. Consequently, this further enhanced the unfavourable pre-existing conditions of stigma in White City, Jabavu.

## **POVERTY AND UNEMPLOYMENT – A SOURCE OF GANGSTERISM, CRIME AND STIGMA**

These phenomena have been persistent in White City and predate its formalization as a residential area. Therefore, the people of White City have generally always viewed themselves as third class citizens of Soweto due the financial constraints caused by their less fortunate socio-economic environment because the more educated Black people built and bought better houses in much better, spacious and attractive surroundings such as Dube Village, Orlando West, Mofolo Central and other better parts of Soweto. Within this environment of poverty and unemployment, the culture of gangsterism emerged as the young and unemployed men tried to redefine themselves and to restore their lost pride, dignity and masculinity. The history of White City is littered with the memories of common criminal gangs called the 'Marashea gang' and 'Bo-tsotsi' which are two of the most prominent gangster names associated with White City even up to this day.

### **THE MARASHEA GANG**

Marashea seem to have taken their name from the 'Russian' victors of the Second World War. They were much feared in White City and their reign of terror extended beyond the boundaries of this township. They usually moved around in groups carrying knob-kierries which are traditional sticks or weapons for fighting and wore the colourful traditional Basotho blankets. The following citation by Kynoch (2000) helps to illuminte this point:

Sesotho culture continues to play a key role in the identity of the Marashea, rivalries are based upon regional origins of the groups within Lesotho, and language, dress and some social customs emanate from Lesotho. During episodes of conflict with non-Marashea groups, Marashea gangs, even bitter rivals unite as Basotho to do battle with outsiders. And lastly, virtually without exception, each group has members who work on the mines and is dependent to some degree on the earning of miners. The Marashea have often been labeled as gangsters because of the criminal pursuits in which they have engaged, but a more accurate categorization might be economic

opportunists. Members of the Marashea have pursued a wide range of income-generating activities, from waged work on the mines (and to some extent, especially prior to 1963, in the factories of South Africa) to a variety of informal sector selling, primarily of liquor and dagga. Finally, some of their activities are blatantly criminal, anti-social practices such as extortion, robbery and assassination. The violent internecine rivalries, as well as the gangs' clashes with the urban youth known as tsotsis, other migrant groups and the police have all contributed to the Marashea's image as a criminal organization. A number of factors distinguish the Marashea from other South African criminal gangs, either past or present. They include the fact that the majority of its members are foreign migrants, the longevity of the association, and its widespread distribution, in areas of Gauteng, Mpumalanga, the Free State and North West (Kynoch, 2000: 80).

Yes, true to form the Marashea gangsters were brutal but even moreso because they could sense the resentment by other residents of White City who regarded their uncivilized ways as barbarian behaviour typical of hillbillies, locally known as 'moegoes', from the rural areas of South Africa and from the relatively backward neighbouring states, in their quest to assert their power and masculinity. Therefore, the Marashea gang was an unwelcome negative ingredient in an already volatile and stigmatized environment of White City.

## **THE BO-TSOTSI GANG**

The tsotsi gangs of the 1940's and the 1950's and other Soweto gangs expressed their masculinity by violent means. Bo-tsotsi fought their street battles with other gangsters using knives such as the then notorious three stars 'Scotch' knife and the dreaded 'Okapi' knife. In the 1960s and 1970s some of the prominent gangs proliferating White City and Soweto were the Hazels, the ZX5s, the Vikings, the Kwaitos, the Damaras, the Dinotshi and the Black Swines and each gang had its own style of dress.

According to Bonner and Segal (1998: 59) the name tsotsi came about this way:

The name tsotsi, derived either from the 'zoot suit' pants popularized by American movies or from the South Sotho word *ho tsotsa* meaning 'to rob', suggested urban slickness and sophistication.

The culture of the 'Bo-tsotsi reigned supreme before 1976 and was a strong and mainly apolitical township gang culture dominated by young men from the 1930's to the early 1970's. As Glaser (2000: 4) puts it:

The tsotsi gangs of the 1940's and 1950's, as well as the Soweto gangs of the 1960's and 1970's, were expressions of young urban masculinity. Although women were sometimes drawn peripherally into gangs as girlfriends, decoys, and lookouts, the gang subculture was essentially male. The distinctive subcultural clothing style was

for males only, and women were excluded from the prestige of spheres of gang life such as fighting. The masculine identity of the gang hinged around fighting skill, independence, street wisdom, proficiency in the *tsotsitaal* argot, and success with women. Adeptness and success in these areas determined a *tsotsi*'s status and prestige as a "Man." Young township women, as trophies of masculinity were subjected to astonishing levels of sexual violence. Male power and control in the gang subculture were underpinned by rape and the threat of rape. *Tsotsis* regarded a jail sentence as a status symbol.

Despite a taste for good music, dress and beautiful women, the youth in White City also and spoke two dialects common in Soweto. Bonner and Segal (1998: 59) capture this phenomenon this way:

On Soweto streets and in its schools, two urban dialects competed for domination. The one was imported into the Meadowlands area of Soweto from the recently demolished freehold townships around Sophiatown and was commonly known first as *flaaitaal* and then more widely as *Tsotsitaal*. The other dialect had spontaneously evolved in the slightly older areas of Soweto, such as Orlando East and West. In the 1960s, it became known as *Isicamtho*, from the Zulu verb *ukuqamunda*, meaning 'to talk loudly or maintain a swift flow of language'. At first, *Isicamtho* was mainly spoken by young men involved in criminal gangs in the area. The two dialects, however, differed considerably since the Meadowlands dialect drew heavily on Afrikaans while the Orlando dialect was based on the Zulu language. Meadowlands' youths derisively labeled youngsters from other areas of Soweto as *kalkoens* (Afrikaans for 'turkeys' after the way in which they supposedly talked). The Afrikaans-based dialect, therefore, gradually gave way to its Zulu-based rival in the 1970s which became a powerful part of black urban culture.

Therefore, out of this discussion one can truly observe that even White City resembles Soweto in many other ways its defining uniqueness is that it has always been distinctly underpinned by a culture of extreme poverty, deprivation, violence and criminal activities which brought down a bad name upon the township and created a stigmatizing environment which was and is still abhorred by many other residents of Soweto.

## **INTERGENERATIONAL COMPARISONS**

Unlike the student generations of 1976 and the early 1980's that fought fiercely to destroy apartheid, the younger generations of the late 1980's and the 1990's are said by the older people in White City to lack a sense of direction and purpose in life because their lives have been easy as they never experienced the hard realities of the apartheid system. They enjoy the

fruits of a democracy for which many people paid the ultimate price of death and that is why many of them, especially the young girls who fall pregnant carry the stigma of abusing the poverty relief grant system for which they never had to fight for.

This intergenerational comparison eulogizes the sacrifices made by the past generations who fought against apartheid and consequently the younger generations who grew up under the new democratic dispensation are criticized for political apathy and their love for a good time, alcohol, drugs and sex. Therefore, when they get infected with HIV/AIDS they have to endure a multiplicity of stigmas associated with the epidemic such as unprotected sex, multiple concurrent sexual partnerships, alcoholism and drug abuse, teenage pregnancy and so on. Other people within the White City environment become judgemental and blame the parents and families of the afflicted individuals for lack of control and lower morality and so secondary stigma affecting the family and other close associates' sets in as they become labeled, blamed, rejected and isolated.

## **THE LOST GENERATION**

These are the heroes of the anti-apartheid struggle who turned into crime because they could not find employment in the post-apartheid South Africa because many of them are unskilled as they had to abandon their studies in their fierce fight to resist apartheid. In the resistance struggles of the 1980's the slogan 'liberation now and education later' was a rallying point for the youth to abandon their studies and partake in resistance struggles against apartheid.

However, post apartheid South Africa seems to have been a disappointment for many of these youths as they resorted to dubious means to make a living. Therefore, crime and the closely related issues of youth culture are among the most important social concerns facing the post-apartheid leadership in South Africa.

The historian Clive Glaser (2000) succinctly summarizes the plight of these former comrades this way:

In the period between the 1976 Soweto uprising and the February 1990 reform initiatives, black urban youth forced the pace of resistance politics throughout South Africa. The so-called "comrades" were the shock troops of resistance: making the townships ungovernable, policing boycotts and stayaways, defying security forces at mass funerals and meetings, rooting out, isolating, and punishing collaborators. Despite their reservations about their immaturity and coercive

excesses, their contribution was seen as positive, sometimes heroic. Since the February 1990 reforms, however, observers have become concerned and often bewildered by the extent of anomie and criminality among the black youth. A large portion of the activist youth felt that they were shunted aside and underappreciated in the negotiation process. Rising expectations were not matched by concrete changes in their way of life. During the 1990's unemployment among the black urban youth spiraled out of control. In 1993 it was reported that fewer than 5 percent of South Africa's school leavers were absorbed into the job market. If anything, the situation has deteriorated since then. A recent survey suggests that over 80 percent of Soweto's population between sixteen and twenty years old, and about 65 percent of those between twenty one and twenty five are unemployed. Many questions have been asked about how to accommodate this so-called lost generation (Glaser: 1).

Yes indeed, the disillusionment and the continuously rising unemployment amongst the youth of South Africa in general, and the youth of White City, in particular further exacerbates the levels of crime and thus does not help to improve the stigmatizing environment of White City which is already laden with other multiple socio-economic factors that help to create further layers of stigma in an already compromised environment with a pre-existing culture of stigma.

### **GOVERNMENT GRANTS – DEPENDENCY, YOUNG WOMEN AND THE ASSOCIATED STIGMA**

This is a structural issue pertaining to the context and socio-economic climate under the new democratic dispensation. The neo-liberal policies of the present ANC government do not help the situation either as more and more jobs are lost with the implementation of the Growth, Employment and Redistribution (GEAR) economic policy (GEAR, 1996).

This means that the lesser educated people from White City have lesser better paying job opportunities if lucky enough to find any job and can therefore not afford to improve their lifestyles by accessing the more spacious and better looking houses in the more affluent parts of Soweto.

The irony of situations is that even though the present democratic government feels obliged in redressing the apartheid imbalances of the past by issuing out relief grants to the following categories of people:

- the very poor and destitute

- the sick including those who are HIV/AIDS positive and are too weak to fend for themselves
- pensioners
- babies and children of single unemployed mothers and so on

The reality of the matter is that checks and balances have got to be weighed against those individuals who abuse this grant system for their own obnoxious ends.

Once again it seems structural issues even under the new democratic dispensation come to the fore in perpetuating the whole cycle of disempowerment, poverty, unemployment and the resultant stigmas. There are serious allegations by people in White City that some young girls of school going age deliberately and repeatedly fall pregnant in order to tap into the grant system as an alternative way of earning a living for themselves and their families. In cases where the young mother becomes HIV/AIDS positive, she apparently receives several grants, one for each child she raises and the other for being HIV/AIDS positive and sick.

Consequently, such girls do not only suffer primary stigma as a result of being HIV/AIDS positive but the stigma rubs onto their children and families in the form of secondary stigma. Other residents view their families negatively, firstly for consistently tolerating their young daughter falling pregnant out of wedlock that being a social taboo on its own. As a result the family's moral standards are questioned and even more so if the sero-positive status of their daughter is known publicly.

Therefore, stigmatization and discrimination against other infected people and their families are a hostile act denigrating those infected and affected by HIV/AIDS. Therefore, it would seem that the presence of primary stigma is often accompanied by secondary stigma directed at those associated with and closest to the infected person.

The historical pre-existing forms of stigma associated with White City seem to be compounded by the latest forms of stigma elicited by the advent and prevalence of HIV/AIDS. What we have here seems to be an enabling environment in which stigma operates at many levels and thereby entrenching a culture of stigma in this township.

This makes for a compelling study of the underlying reasons and social factors at play in this whole HIV/AIDS tragedy and therefore the next discussion will be on the rationale of this study to further explain in detail why this study was so compelling to do.

## **1.4 RATIONALE**

This study is sociologically compelling because of the high death rate and suffering affecting many people in South Africa and many other parts of the world.

Of all regions and countries of the world, Sub-Saharan Africa is hardest hit by HIV/AIDS and it is also well known and documented that within the region, South Africa is one of the leading HIV/AIDS afflicted countries in the world. Many people will apparently die before their 48th birthday and it is also projected that by 2010 the life expectancy will be 43 years. This scourge is ravaging families and communities and the poorest sectors in society suffer the most because they lack the necessary financial resources that will help them access better treatment and care at private institutions, as accessed by the financially better off members of society. Politicians, healthcare workers, business people, civil society organisations and other stake holders constantly highlight the perils of this ominous disease and advise the public, especially the youth to be very cautious and practice safe sex whenever they feel like having sex with their partners. Many stories and gossips abound in the townships of people who died of HIV/AIDS related diseases and yet their families and loved ones avoided mentioning the real cause of death. The following statement below helps to illustrate the point about the seriousness of the epidemic in South Africa:

Home to more than 5 million people living with HIV/AIDS, South Africa is one of the countries hardest hit by the AIDS epidemic. South Africa's HIV/AIDS prevalence rate (the percentage of people living with HIV/AIDS) is among the highest in the world, although prevalence rates have begun to stabilize and there is evidence that the epidemic may be declining among certain populations. The epidemic has already had a profound impact on many aspects of South African society and is projected to affect the country's demographic structure and its economic, education, and health sectors if more is not done to stem its tide. As a middle-income country of significant political and economic importance in the African continent, the future course of the HIV/AIDS epidemic in South Africa will have broader implications for Africa overall (The HJKFF, 2008).

Despite numerous programmatic efforts by the South African government HIV/AIDS still remains a serious problem. The government created structures such as the National Aids Coordinating Committee of South Africa (NACOSA) in 1992 and a subsequent review of the impact of NACOSA in reducing the HIV/AIDS prevalence levels led to the creation of a new structure, known as the South African National AIDS Council (SANAC), to take charge of

formulating policy and strategy, coordination and mobilization of national resources in the fight against this epidemic.

The ‘HIV and AIDS and STI Strategic Plan for South Africa 2007–2011’ is a new five year plan established in March 2007 to help as a guideline for the country’s vast government, non-governmental and civil society networks geared towards fighting this scourge (The NSP, 2007).

The following statistics are a national breakdown of the prevalence levels by province in a study conducted by the South African Department of Health in 2007:

Table 1: HIV prevalence (%) by province 2002-2008

<b>Province</b>	<b>2002</b>	<b>2005</b>	<b>2008</b>
KwaZulu-Natal	11.7	16.5	15.8
Mpumalanga	14.1	15.2	15.4
Free State	14.9	12.6	12.6
North West	10.3	10.9	11.3
Gauteng	14.7	10.8	10.3
Eastern Cape	6.6	8.9	9.0
Limpopo	9.8	8.0	8.8
Northern Cape	8.4	5.4	5.9
Western Cape	10.7	1.9	3.8
National	11.4	10.8	10.9

The results of this study suggest that KwaZulu-Natal, Mpumulanga and Free State have the highest HIV prevalence. However, the relatively small sample sizes may limit precision, and in several cases the ranges of uncertainty overlap. (<http://www.avert.org/safricastats.htm>).

The above statistics illustrate the seriousness of the proliferation of HIV/AIDS in South Africa. As can be seen, in the year 2008, a slight decline in the rate of infection has been recorded in Gauteng province but nevertheless 10.3% is a figure of concern considering the fact that Gauteng is the smallest province but the most densely populated. In their ‘Mid-year population estimates of 2010’ Statistics South Africa (Statssa, 2010) published official statistics recording over 11 million residents of Gauteng, translating into 22,4%, of the national population of over 49 million people. Furthermore, the HI virus has been observed to have the capacity to mutate and become drug resistant, as in the case of Multiple Drug Resistant (MDR) and the Extremely Drug Resistant (XDR) strains of tuberculosis. This development is a complicating factor towards winning the war against this disease.

Lee, Esterhuysen, Steinberg and Schneider (1996) conducted a study on HIV/AIDS demographic modelling in Soweto using the 'Doyle model' to project the growth patterns of HIV/AIDS in Soweto until 2010. Variations of scenarios termed, high, medium and low were created with simulations depending on the average number of sexual partners, condom usage and successful treatment for sexually transmitted infections. Results showed that the projected HIV/AIDS prevalence rate by the year 2010 was as follows: 24% for the high scenario corresponding to 343,000 deaths, 15% for the medium scenario corresponding to 222,000 deaths and 8% for the low scenario corresponding to 118,000 deaths. Lee et al. (1996) estimated that by the year 2010 HIV/AIDS related deaths will be responsible for 28% - 52% of all deaths translating to a figure ranging from 135,000 – 270,000 of all deaths in Soweto for that year.

This scenario illustrated above is not good makes it even more compelling to undertake a related study focusing entirely on gaining an insight and understanding of how HIV/AIDS related stigma unfolds and impacts on the affected people of White City.

Furthermore, many people report that their close friends, neighbours and relatives affected by HIV/AIDS felt unfairly treated betrayed and alienated from their communities as soon as their loved one's positive HIV/AIDS status became known in their communities. During the course of the researcher's work as a regional manager for the Gauteng Provincial Health Promotion Department, dating back from 1991 up to the year 2000, he has seen vast resources invested by the government and the private sector in the form of money, personnel, education, literature, condom supply, research, legislation, policy and many other supportive and combative ventures geared towards arresting the spread of this disease. However, all efforts seem not to be having a noticeable impact in reducing the number of infected people as well as in changing attitudes that promote and sustain unsafe sexual practices.

The researcher is then compelled to ask the question but why? What could be the other undercurrent sociological factors that are equally important in this whole HIV/ AIDS tragedy? These questions are asked more especially in consideration of the fact almost all of the affected people known, never admitted nor confided to anyone within their circles that they were affected by HIV/AIDS. At this stage it can only be speculated that the fear of being stigmatized is the reason for their silence! Most of these affected people become introverts by resorting to secrecy and withdrawing from the social scene and the publicity they previously used to value and enjoy so much. This culture of secrecy often robs the affected families of

the support, warmth and possible financial and material help that they could have received from some others who care about them. It is only after most of these affected families have buried their loved one that many people learn through the grapevine about the deceased's HIV/AIDS status. The deceased's family and close associates seldom mention the real cause of their loved one's death for fear of secondary stigma. As a result many families ascribe the death of their loved ones to common and socially accepted illnesses such as Tuberculosis (TB) and meningitis, which have the propensity to induce a lot of sympathies for the bereaved families. The veil of secrecy by families around HIV/AIDS related deaths is symptomatic of a stigmatized environment whereby people are afraid to be associated with someone who died as a result of HIV/AIDS.

The seriousness and impact of this HIV/AIDS pandemic is felt most acutely if the diseased was the breadwinner of the family. In the case where the husband and wife both passed away as a result of the disease, it is very sad to see and hear their orphaned children asking for help in terms of paying for their school necessities as well accessing money necessary for their daily survival. In some instances, it is often the teenage children who speak about the hardships of having to endure the taunts from other members of society regarding insensitive comments they make alluding to the 'undignified' nature of their parents' death/s. Therefore, it seems quite likely to me that this culture of secrecy around HIV/AIDS may be as a result of the 'stigma' attached. Primary stigma seems to be directed to the infected person and secondary stigma becomes directed to people around them. Therefore it is imperative to note that there is a symbiotic relationship between primary and secondary stigmas as one is dependent upon the other.

In South Africa there is considerably a lot of literature on primary stigma but there is relatively very little literature available on secondary stigma. Therefore, more research on secondary stigma needs to be carried out in order to understand its social structures and how they function. A fuller understanding of what triggers this phenomenon called secondary stigma and the environment in which it thrives will go a long way in helping social scientists to formulate plans and methods that will help to eradicate this cruel phenomenon.

## **1.5 METHODOLOGY**

In order to address the research question, the qualitative research method was used with the aim of investigating the hardships of HIV/AIDS affected people in relation to their experiences of secondary stigma.

## **SAMPLING AND SAMPLE SIZE**

The sample consisted of a cross section of 15 ordinary adult men and women of White City, Jabavu over the age of 18 who have been affected by HIV/AIDS. However, the selection criteria when choosing this cohort was not based on variation in terms of gender, income, age distribution, kinship, spatial proximity, generational links, obligations and other such factors but simply on the fact they have been affected by HIV/AIDS due to their association with someone known to be infected by HIV/AIDS. Therefore, their experiences matter the most and are the primary focus of this study.

Purposive Sampling was employed with the assistance of the 'Gauteng Home –Based Care', a non-governmental organisation (NGO) which is affiliated to the Anglican church of South Africa. This sampling method was chosen because of the following reasons: The research participants live in White City, are known to the community health workers, are easily accessible and trusted by them, are willing to participate in the study, can speak more than one of the official languages in South Africa, are affected by HIV/AIDS and therefore are the regular clients of the community workers. After explaining the purpose of the study to each identified research participant, it was categorically explained by the community workers that absolute confidentiality will be ensured at all times and that participation was voluntary and each participant was free to terminate their participation in the study as soon as they felt uncomfortable to continue.

Interviews comprising semi-structured and open-ended questions were conducted whereby people got to talk about the story of their lives starting off with simple non-threatening questions and moving on to the more complex ones. The interview guide is attached as Appendix-A of this research report.

## **MEASUREMENT**

Coding and analysis was done using the nominal scale. Codes, labels and categories were assigned to data that is qualitative (non-numerical) so that specific patterns and themes could be drawn during analysis. Similar responses were grouped together under specific themes in order to determine formations of any patterns of behaviour, as well as establishing any possible causal and co-relationships between and across the spectrum of data. Numeric and colour codes were used as symbols to help highlight common themes so as to establish the

frequency of significance for each and every thematic category identified for analytical discussion.

## **DATA ANALYSIS**

Using an interdisciplinary approach, the discourse analysis method was used, to analyse data arranged into themes that are not mutually exclusive nor mutually exhaustive because of their interlinkages.

## **ETHICAL CONSIDERATIONS**

This is especially meant to protect the subjects of research as a result of the sensitive nature of HIV/AIDS.

A consent form was signed by both the respondent/s and the researcher stating the true nature of the research and making the respondent aware that he/she can pull out of the interview process at any stage if they so wish. A confidentiality clause was included as part of the consent agreement guaranteeing absolute confidentiality to respondents. It was stated in the consent form that the participants' names and other particulars will be held in the strictest of confidence and will never be divulged to anybody. Several telephone numbers, for counselling purposes were included on a separate list to make it easier for the participant/s to receive help and support should the need arise. A sample of the consent form was attached as Appendix – B, a list of counselling resources was also attached as Appendix – C, a list of counselling resources was attached as Appendix – D and lastly, a participants' information sheet was also attached as Appendix – E.

Confidentiality was guaranteed in consideration of sensitivities around the nature of the data and human rights related issues that are inherent in the study of this nature. A form asking for permission to use a tape-recorder was administered specifying that if respondents do not feel comfortable with the use of the tape-recorder then their wish will be respected and therefore, it will not be used. Data collected is stored in safe lock up cupboards in a special room at home.

Ethical approval was granted unconditionally by the 'Human Research Ethics Committee' of the University of the Witwatersrand and the Ethics Clearance Protocol Number is HO 90624.

## **THE STRENGTHS OF THE REPORT**

All 15 interviewed research participants were very open and generous in sharing their lived experiences and their deep-seated feelings about HIV/AIDS, secondary stigma and life in general in White City, Jabavu. Data saturation point was reached when the same themes kept on re-emerging during interviews with different participants. However, these themes as discussed in the data analysis section are not mutually exhaustive nor mutually exclusive as they are strongly interlinked with poverty and unemployment as the overarching themes.

However, the researcher feels that this study has developed into an ambitious project for a Masters (MA) by coursework and research report. Therefore, whilst the initial project was fairly narrowly conceived, the findings from this research drove the researcher to explore, at some considerable length, two principal areas which were not part of the original conception of the project. These two areas are:

1. The researcher's argument that stigma in White City must be understood in the broader context of pre-existing forms of stigma which he asserts create a "stigmatizing environment" in which new forms of stigma find a fertile social, cultural and economic world in which to take root and flourish.
2. The researcher's recognition that the manner in which the research participants develop coping mechanisms to deal with their experiences of secondary stigma is a critically important dynamic in understanding the experiences of stigma among those research participants.

Therefore, as it stands, it is the humble opinion of the researcher that the Report goes beyond what might normally be expected of a research report, by moving beyond the concerns raised in the literature he worked with.

## **LIMITATIONS OF THE REPORT**

However, there are two considerable methodological limitations in this study. The first is the unavoidable usage of purposive sampling as a non-probability method, executed with the help of the 'Gauteng Home-Based Care' staff in this study because that may have possibly

excluded valuable input by other people not associated with this home-based care NGO and yet being equally if not more so affected by HIV/AIDS Secondary Stigma in White City. However, despite that fact it must be appreciated that without the collaboration of the dedicated staff of this NGO, this study would probably be impossible to begin considering the fact that: 'How could one singularly identify, select, access and enlist the voluntary cooperation of the research participants'? Therefore, the benefits of choosing the purposive sampling method and also employing the help of the above mentioned NGO as an entry point into the community far outweigh the difficulties and disadvantages that could have been encountered by the researcher in the pursuit of the execution of this study.

Finally, another limitation of this study is that as a result of the small sample size of 15 research participants, the findings of the study could not be generalised to the greater population of Soweto in consideration of issues such as the traditionally overly negative socio-economic conditions unique to White City, kinship, friendship, closeness, gender, age, generational links, spatial proximity, obligations and other such relevant factors.

## **1.6 CONCLUSION**

Therefore, having followed all the necessary social research methods and procedures, an attempt was made in this study to look deeply into HIV/AIDS related secondary stigma in White City. Understanding this kind of stigma is imperative in giving more insight and knowledge so much necessary in the fight against the scourge of HIV/AIDS which has the propensity to annihilate large segments of the South African population. No effort must therefore be spared by all sectors of society in the final onslaught to eradicate this disease. The next chapter develops a theoretical framework for the investigation of secondary stigma in White City by a review of the literature on stigma and HIV/AIDS related stigma.

## **CHAPTER 2**

### **LITERATURE REVIEW AND THEORETICAL FRAMEWORK**

## **2. INTRODUCTION**

This chapter seeks to locate the research that has been done in the context of the literature on stigma. The central concern of this research report is to understand the dynamics of HI/AIDS related secondary stigma in White City, Jabavu, which as we have discussed in chapter one has been a township plagued by a culture of stigmatisation.

The word stigma comes from the Greek and refers to being marked (burned or stained) to distinguish someone as a perpetrator of some bad action or behavior. Stigma was the word given to the burn mark or the stain. The literature review on stigma reveals Erving Goffman as the classical champion on the study of this concept and is therefore credited for laying the theoretical perspective that other authors later relied on and developed in their studies.

### **2.1 CONCEPTUALIZATION OF STIGMA: PRIMARY AND SECONDARY STIGMA**

In his classical book entitled “Stigma: Notes and Management of Spoiled Identity”, Goffman (1963: 43) acknowledges the existence of secondary stigma and refers to this kind of stigma this way:

In general the tendency for a stigma to spread from the stigmatized individual to his close connexions provides a reason why such relations tend either to be avoided or to be terminated.

This quote by Goffman is an illustration that vindicates him in the court of some critics whose allegations imply that Goffman’s classical work on stigma was devoid of an awareness of the existence of secondary stigma which is more of a social phenomenon rather than a physical, psychological, biological or medical condition.

Goffman (1963: 43) further explains the relationship of the normal person and the afflicted this way:

The person with courtesy stigma can in fact make both the stigmatized and the normal uncomfortable: by always being ready to carry a burden that is not ‘really’ theirs, they can confront everyone else with too much morality; by treating the stigmas as a neutral matter to be looked at in a direct, off-hand way, they open themselves and the stigmatized to misunderstanding by normals who may read offensiveness into their behaviour.

Goffman (1943) further points out that the people suffering from courtesy stigma are significant models of ‘normalisation’ a term which he distinguishes from ‘normification’

which is a process he describes as an effort by the individual suffering from primary stigma to behave normally like ordinary unstigmatized people even though no effort is made to hide the root cause of the stigma.

Primary stigma is essentially the type of stigma directed at the diseased person whose behavior is considered to be socially unacceptable by the others. Therefore, primary stigma operates basically on two levels which are first, felt or perceived stigma and secondly, enacted stigma.

Felt stigma is an internalized form of stigma and usually results in perceived feelings of social isolation and rejection coupled with feelings of shame and guilt by the victim. Brouard and Wills in a publication by the United States Agency for International Development (USAID, 2006: 1) describe felt stigma this way:

“Internal stigma” – also described as felt, imagined, or self stigma – is the product of the internalization of shame, blame, hopelessness, guilt, and fear of discrimination associated with being HIV-positive. It can affect caregivers and family members, who also may internalize feelings of shame, guilt, or fear.

Brouard and Wills (USAID, 2006) explain that felt or internal stigma can have a profound negative effect in the fight against HIV/AIDS because as they point out, by adhering to the social script of expectations, a mother in India continued to breastfeed her baby even though she was HIV positive to avoid suspicion of infection by neighbours and other close associates. Accordingly, associating HIV/AIDS with death makes a fearful man in Botswana skip participation in the country’s national ARV treatment campaign. Another example is that of the Cambodian woman who is a sex worker but chose not to visit the clinic regularly for the treatment of sexually transmitted infections (STIs) because she feared being judged and ridiculed by the clinical staff. Brouard and Wills (USAID, 2006) further cite an example of a couple in Haiti who lived in fear of disclosing their HIV status and thereby delaying making plans for the future care and support of their children in the event of their death.

On the other hand enacted stigma is an externalized kind of stigma and refers to the verbal, physical and other abusive behavior directed at the victim.

Brouard and Wills (USAID, 2006: 1) describe enacted stigma as:

“External or enacted” stigma is rooted mainly in fear and judgment of what is different, leading to blame, distancing, and discrimination. It is an attempt to promote social order but, ironically, it breaks down communities.

Brouard and Wills (USAID, 2006) explain that both felt and enacted stigma are examples of stigma and discrimination suffered by many people living with HIV/AIDS, other vulnerable groups and their families.

Felt or perceived stigma as well as enacted stigma are therefore not restricted to the primary victim of stigma but can also extend by virtue of association to the families and close associates of the primary victims.

The concept of stigma is even more relevant today considering the labelling and isolation of people with chronic and contagious diseases such as HIV/AIDS.

Stigma affects the social identity of an individual and those people stigmatized are characterized by a very low self-esteem, feelings of inferiority and a feeling of being less human than other people. As Goffman (1963: 12) puts it:

He is thus reduced in our minds from a whole and usual person to a tainted, discounted one. Such an attribute is a stigma, especially when its discrediting effect is very extensive; sometimes it is called a failing, a shortcoming, a handicap.

Goffman (1963: 15) goes on to explain:

We and those who do not depart negatively from the particular expectations at issue I shall call the normals.

Furthermore, Goffman (1963) in Deacon, Stephney and Prosalendis (2005: 15) is cited as suggesting that:

...people who possess a characteristic defined as socially undesirable (HIV/AIDS in this case) acquire a ‘spoiled identity’ which then leads to social devaluation and discrimination.”

Goffman explains the phenomenon of stigma as a deliberate labelling effort by others to reaffirm their ‘normalcy’ by highlighting the perceived or real abnormalities in another person. Therefore, Goffman reiterates primary stigma as that being suffered by the diseased person and secondary stigma as that being suffered by people closest to the diseased person such as family members, friends and care givers by virtue of their association with the sick person. Goffman (1963: 30) explains that:

The individual who is related through the social structure to a stigmatized individual – a relationship that leads the wider society to treat both individuals in some respects as one. In general, the tendency for a stigma to spread from the stigmatized individual to his close connections provides a reason why such relations tend to be avoided or to be terminated.

In line with the context of this study secondary stigma comes as a result of some people in society who view HIV/AIDS as a disease visited upon the sexually promiscuous people and other people of lower morality such as sex workers, homosexuals, drug addicts, the poor and so on. Therefore, when infected this category of people would further suffer what Goffman (1963) would classify as double or compound stigma.

Even though Erving Goffman's (1963) classic study on stigma focused more on individual mental illness, physical deformities and what were perceived to be socially deviant behaviours, his enlightening theoretical framework on stigma nevertheless enabled other authors and academics to add more insights and perspectives to his limited but useful theory. A discussion below points out to one of these added perspectives by other authors and academics who emphasize more on the social dimension of stigma and its consequences.

## **2.2 SOCIAL PERSPECTIVES OF STIGMA**

As pointed out earlier Goffman's conception of stigma did not go uncontested and consequently authors and academics such as Deacon, Stephney and Walker (2005: 15) explain that:

Various authors have challenged the tendency in much psychological work to see HIV/AIDS stigma (or, indeed, any disease stigma) in individual psychological terms (for example, Link & Phelan 2001; Parker and Aggleton 2003). Alonzo and Reynolds for example, provide a more complex reading of Goffman, suggesting that stigma is not merely an attribute, but represents a language of relationships, as labeling one person as deviant reaffirms the normalcy of the person doing the labelling" (Alonzo and Reynolds, 1995: 304).

Using Goffman's theoretical framework other researchers and authors in the field of epidemiology have since gone further to develop the understanding of the concept into a broader and more holistic theoretical perspective. In the context of chronic diseases, more especially HIV/AIDS, stigma can be viewed in two dimensions. Firstly, it can be viewed on a biological level and attributed to a pathogenic agent invading the body. Deacon, Stephney and Prosalendis (2005: 19) put forward two proposals in trying to distinguish between the biological and social categories of stigma:

(1) In their first proposal, disease stigma can be defined as an ideology that claims that:

... People with a specific disease are different from 'normal' society, more than simply through their infection with a disease agent. This ideology links the presence of a biological disease agent (or any physical signs of a disease) to negatively-defined behaviours or groups in society. Disease is thus negative social 'baggage' associated with a disease.

(2) In their second proposal Deacon, Stephney and Prosalendis (2005: 23) further assert that:

Disease stigmatization can be defined as a social process by which people use shared social representations to distance themselves and their in-group from the risk of contracting a disease by: (a) constructing it as preventable or controllable; (b) identifying 'immoral' behaviours causing the disease; (c) associating these behaviours with 'carriers' of the disease in other groups; and (d) thus blaming certain people for their own infection and justifying punitive action against them.

Blaming HIV/AIDS affected people is a social aspect of stigma manifesting itself in the form of secondary stigma directed at those closest to the infected individual and it is the core business of this research. This study sets out to unearth the opinions and experiences of the affected people who suffer social injustice as a result of those entrenched social tendencies and patterns of behaviour that set to isolate them together with the infected people from the mainstream of society.

The issue of punishment delivered upon infected people is of concern considering the post-1994 democratic culture of human rights in South Africa. Implicit in the term 'punishment', which may include various levels of physical, emotional and psychological abuse, is the underlying process of discrimination and the fundamental question is: how can then people with a history of sordid discrimination like South Africans still persist in discriminatory actions even well after the demise of apartheid? The answer lies partly in Deacon, Stephney and Prosalendis (2005: 41) who cite the following authors, Herek and Capitano (1998) and Herek (1986, 2002) using the term 'instrumental stigma':

...to describe intended discrimination based on an inflated fear of contracting HIV, as well as intended discrimination based on resource concerns due to judgments about the likely social contribution of a person living with HIV/AIDS.

Cited in Stein (2003) Herek and Capitano (1993) further explain that:

With particular reference to the function of stigma in a society, then, stigma can be seen as instrumental, arising from utilitarian self interest, or symbolic, arising from a value-based ideology. Instrumental stigma allows people to distance themselves from the fear of infection, and symbolic stigma is based on moral judgments.

Therefore, stigma is a form of discrimination which in turn has the propensity to induce fear, estrange people and subsequently discourage people from seeking HIV/AIDS treatment, counseling and testing.

Stigma thus operates by producing and reproducing social structures of power, hierarchy, class, race, ethnicity, health status, sexual orientation, and gender into inequality (ICRW, 2002).

This categorizes discrimination as a violation of human rights especially in light of the constitution of the present day Republic of South Africa which stipulates that accessing health care is a fundamental human right (The CRSA, 1996).

Furthermore, some people in society consider the infected to be physically contaminated or polluted and thus a threat to society. This perception of 'being a threat' to society is extended to people closest to the infected and as a result they suffer secondary stigma which has already been identified as some form of discrimination. The irony is that human interactions are dynamic considering the fact that some of the people who are infected were very popular and productive members of society and yet they become stigmatized and alienated together with their loved ones and close associates as soon as their unfavourable health status becomes known. It would seem that Giddens (2008: 8) was accurate in his observation when he explained that human relationships are not structured to be permanent like physical buildings.

Social relationships are dynamic and structuration is a conscious and subjective human process that is value laden. The 'pull and push' character of social interaction is not independent from individual choice or agency and therefore decisions are made in terms of the negative or positive value that a particular interaction will bring to the relationship.

HIV/AIDS is underlined by negativity and many people choose to refrain from interacting with the infected out of ignorance and the fear of contagion. Infected people and their loved ones become labeled as a social risk because of their perceived 'contaminated' status and hence they become isolated from society.

In their studies, Alonzo and Reynolds (1995: 304) observed and further articulate this notion of discrimination and define stigma and those stigmatized in terms of discrimination:

The stigmatized are a category of people who are pejoratively regarded by the broader society and who are devalued, shunned or otherwise lessened in their life chances and in access to the humanizing benefit of free and unfettered social intercourse.

This definition entails a sociological perspective whereby stigma is viewed as a social construct used to discriminate against other people by some sections of the broader society which looks down upon them.

This makes out stigma to be a bad thing and Newman (2007:1) puts it this way:

Stigma is viewed as a mark of disgrace and infamy; a stain or reproach, as of one's reputation, a sign of social unacceptability.

Language and its negative power is one of the primary vehicles through which stigmatization occurs. A community leader in Zambia explained that:

It is not sometimes the disease that kills these patients, it is the bad words and remarks from people. Gossip has harsher consequences for women who generally rely more heavily than men on social networks, particularly when their access to and control of economic resources is limited, as in our study" (ICRW 2003: 38).

Ultimately, the following actions may serve as a recourse or as coping mechanisms by the stigmatized in coming to terms with their situation. 'Disclosure' is one option if one happens to have a very strong family support structure or a supportive environment. Some people turn to religion to reclaim their humanity and to make peace with God, whilst others may seek other explanations.

Stigma is then a negative and brutal concept that dehumanizes the infected people, their families and others closest to them. It reduces them to fair-game as they become perceived as social outcasts that can be ridiculed, rejected and isolated by anyone who so wishes to in the community. Hurtful gossips, attitudes and comments abound about the infected people and their health status. People who used to be friendly develop unfriendly attitudes, opinions, comments and thoughts about their family members, colleagues, neighbours, friends and acquaintances.

Now let us reinforce our discussion by exploring further the concept of AIDS related stigma and see what has generally been said. Altman (1986: 34) states that:

Stigma is largely a result of the initial discourse around AIDS, which fitted mostly into the medical and the medico-legal categories. This discourse linked AIDS to promiscuous homosexuals, creating the impression that promiscuity and 'aberrant' sexualities as such were the cause of AIDS, rather than a virus. Not surprisingly this lead to the conclusion that whoever had AIDS was promiscuous.

It would appear that stigmatization is an irrational process and therefore, it becomes very difficult to understand especially in the context of HIV/AIDS whereby there is still a lot of defensive behaviour and blame apportionment as a result of ignorance and fear.

As Jackson (2002: 4) puts it:

Stigmatizing others and finger-pointing have marred every stage of the epidemic around the world and led many African governments to deny the AIDS epidemic in the early days. Those that did not deny it such as the governments of Uganda and Kenya, were heavily penalized. In the 1980's Uganda was labeled the "AIDS capital of the world" and tourism to Kenya plummeted.

The common thread amongst all kinds of stigma, whether primary, secondary or multi-factorial, is the negativity surrounding it. It is generally accepted that there is a relationship between HIV/AIDS, racism, sexism and disability prejudice because all can be used to stigmatize other people. The only difference between the four is that the causal factors of HIV/AIDS are acquired whereas with the others, biology or genetics plays a very important role from conception, to birth and thereafter throughout life.

In explaining HIV/AIDS stigma, Herek (2002) in Deacon (2005: 15), contextualizes Goffman's definition of stigma by:

...defining HIV/AIDS stigma as an enduring attribute of an individual infected with HIV that is negatively valued by society and thus disadvantages people living with HIV/AIDS (PLHA's).

However, other researchers cite exclusion as a function of the political economy present in the world today that perpetuates social inequalities in order to maintain the status-quo tipped in favour of the powerful social groups. Gay men, African immigrants, Blacks, Sex workers and Drug users are blamed and thus stigmatized through a dual association of promiscuity and poverty.

Ultimately, therefore, stigma is linked to the workings of social inequality and to properly understand issues of stigmatization and discrimination, whether in relation to HIV and AIDS or any other issue, requires us to think more broadly about how some individuals and groups come to be socially excluded, and about the forces that create and reinforce exclusion in different settings (Parker and Aggleton 2003: 16).

Furthermore, on an individual level, related sicknesses that are the indirect markers of HIV/AIDS, such as tuberculosis, cancer, meningitis and others, can make it easy for people living with the disease to deny their status in an effort to avoid stigmatization because as a

syndrome HIV/AIDS manifests itself in other forms such as an affliction by tuberculosis (TB) due to the compromised immune system. Therefore, an infected person can falsely and simply say that he/she is suffering from TB which is considered, with much more understanding and sympathy than HIV/AIDS, because it is a curable disease.

Deacon (2005: 12) explains:

On the other hand, ...at a social level, however, the 'invisibility' of HIV infection exacerbates stigmatization and encourages people to use secondary markers (such as wasting or the onset of illnesses such as TB) to identify who has the condition. The absence of visible evidence of how large the pool of infected people is, and who is infected, encourages the idea that HIV/AIDS affects 'other' people.

Stigma and discrimination are the two terrible twins that perpetuate the violation of basic human rights such as freedom and non-discrimination. A social environment that enables the transgression of human rights legitimizes the practice of stigmatization and discrimination.

Anne Loohuis (2007: 23-24) as cited in Stadler (2007) offers further illumination by noting that stigmatization takes place within a certain context. She then lists the following causes of stigmatization within the HIV/AIDS context:

- Firstly, HIV/AIDS is associated with abnormal or bad behavior.
- Secondly, infection is the result of irresponsible behavior such as having sex without using a condom or sharing infected needles.
- HIV/AIDS is caused by immoral behaviors and the person is seen as an immoral bad person.
- HIV/AIDS is an infectious disease and it is dangerous for society.
- HIV/AIDS is associated with death.
- HIV/AIDS is not well understood and the health services have a negative outlook on the illness.
- Society does not associate easily with people living with HIV/AIDS and therefore, people living with HIV/AIDS are outcasts.

A press report by Kortjaas and Msomi (1998) reported that in South Africa stigmatization led to the murder of Gugu Dlamini. She disclosed her sero positive status in the context of a world AIDS Day meeting and was killed by a mob a few days later for 'bringing disgrace to the community'. For those affected or infected by HIV, primary and secondary stigmas have been identified as some of the factors that make it more difficult to cope with the disease and with death."

Therefore stigma makes people more vulnerable and secretive about their sero positive status. They fear being rejected by their lovers, neighbours, the general community as well as the real fear of losing their jobs and complicating life for their families, loved ones and those left behind grieving for them when they are dead.

### **2.3 HIV/AIDS, STIGMA AND DISCRIMINATION**

Since the discovery of HIV/AIDS in by American scientists in 1981, it has elicited very strong reactions; so much that Simbayi et al (2007) in Gilbert and Walker (2009) stated that HIV/AIDS is perhaps the most stigmatized condition in the world. Goffman also expressed that diseases associated with the highest degree of stigma share common attributes (Gilbert and Walker, 2009), the disease is progressive and incurable, the disease is not well understood amongst ordinary members of the public and symptoms cannot be concealed. Accordingly, HIV/AIDS fits this profile and more so because it is mostly sexually transmitted much morality is attached to it hence it becomes easier to apportion blame on individuals or groups that are regarded as a high risk such as prostitutes, homosexuals and intravenous drug users as they are seen as engaging in immoral behaviors. In order to identify the usefulness of the concept of stigma, this study briefly makes use of the typology of modes of adaptation to epilepsy, adjusted and unadjusted adaptations. Adjusted individuals are those able to effectively neutralize the negative impact of epilepsy on their lives and an unadjusted individual is the opposite of the adjusted one.

Scambler and Hopkins (1986), using the same study of epilepsy, came up with the same model based on the distinction between ‘enacted’ stigma and ‘felt’ stigma and they called it the hidden distress model of epilepsy. Enacted stigma refers to discrimination by others on the grounds of being imperfect and felt stigma involves an internalized sense of shame and immobilizing anticipation of enacted stigma – i.e. the fear of being discriminated against. The overall results were that felt stigma is more disruptive amongst the adults with epilepsy than enacted stigma. Therefore, in relation to chronic stigmatizing conditions, HIV/AIDS can be linked to the hidden distress model. There have been and still are persistent negative social responses that play a role in the experience of individuals living with HIV/AIDS. Individuals may prefer adjusted adaptation for instance, in which they are able to publicly disclose their sero-positive status in an attempt to side step any hostility and educate others or alternatively choose to disclose their positive status to a chosen few individuals.

Alonzo and Reynolds (1995) in Scambler (2009) identified four phases of an HIV stigma trajectory. These phases are also useful in explaining the responses to the HIV/AIDS epidemic and people living with HIV/AIDS. The first stage is filled with uncertainty where the individual suspects that behaviours might put him at risk and the phase can end with the testing for HIV. The second stage involves diagnoses of the virus and stigma becomes important to a point where disclosure needs to be negotiated. The third phase is living between health and disease, symptoms are not visible and the individual can conceal their status. However, the last stage is the passage to social and physical death, symptoms are visible and felt stigma may be associated with isolation. For emphasis' sake and to further expand on the concept of stigma Scambler (2009) put it this way,

Stigma is typically a social process, experienced or anticipated, characterized by exclusion, rejection, blame or devaluation that results from experience, perception or reasonable anticipation of an adverse social judgement about a person or a group.

This above statement shows how negativity underlines the HIV/AIDS epidemic as well as the people living with it. They are viewed as deviating from the normal, normality in this context relating to individuals straying away from the norms and values of society. People living with HIV/AIDS as already explained are blamed for their own disease based on the fact that they engage in risky behavior such as prostitution, multiple concurrent sexual relationships, homosexuality and intravenous drug abuse. Therefore, society's response to people living with HIV/AIDS is to stigmatize and to discriminate against them. It is also important to differentiate between stigma and deviance. Stigma is an ontological deficit reflecting the violation against social norms and values whereas deviance is a moral deficit reflecting the violation of social norms and values. Furthermore stigma invokes shame whilst deviance invokes blame but it should be noted that deviance is a component part of stigma accompanied by other constituent parts such as labeling and stereotyping discrimination. As a result people infected and affected by HIV/AIDS express a lot of fear of being stigmatized and consequently discriminated against. Scambler also argues that stigma acts as an obstacle to good health and a barrier to health care for those shamed and blamed. In most cases then HIV positive individuals hide their status from family, friends, partners and employers for fear of being ostracized. This fear also prevents them from getting medical assistance and receiving ARV treatment. Additionally family members are often condemned and stigmatized by virtue of their association with a member who is HIV/AIDS afflicted.

A study undertaken by Gilbert and Walker (2009) in an HIV/AIDS clinic in Johannesburg showed that the fear of stigma plays a significant role in patients' experiences of the disease from the early stages of testing and disclosure to the initiation of and commitment to ARV therapy. People living with HIV/AIDS are discouraged by factors such as moral judgement and blame as well as relationship termination and verbal and physical abuse. Thus, stigmatized individuals suffer discrimination that can lead to loss of employment, housing and estrangement from family and friends. This fear of being stigmatized and discriminated against can also lead to many people not declaring their positive status to their spouses and partners which is a dangerous practice because they pass on the infection. According to Scambler (2009), HIV positive individuals who express projected stigma and deviance consciously reject the attribution of shame and blame. Nevertheless, they still face verbal and physical abuse, accusations for publicly announcing their sero-positive status and thus bringing shame to their communities as happened in the case of Gugu Dlamini, a woman from Kwazulu Natal, who was murdered for publicly disclosing her HIV/AIDS positive status.

Posel, Kahn and Walker (2007) argue that AIDS intervention and prevention campaigns have often ignored the social and cultural contexts in which they have been implemented. The absence of local social knowledge around sexual norms has often resulted in limited interventions. Their study showed that pervasive and virulent stigma attached to AIDS compounds the fear and mysteriousness surrounding the epidemic by shifting opportunities for open public discussion on the subject. Parker and Aggleton (2003) also emphasized that power is central in defining stigma especially in relation to HIV/AIDS and in order for the co-occurrence of components of stigma such as labeling, stereotyping discrimination, power must be exercised. Thus, for those people holding power, they decentralize it in communities, making it easy for people to adopt ways of stigmatizing and discriminating other people.

## 2.4 SECONDARY STIGMA AND HIV/AIDS PREVALENCE

Secondary stigma as cited before refers to prejudice and discrimination directed at people associated with those infected by HIV/AIDS. This is the least studied of the three primary forms of HIV/AIDS stigma and it is the bedrock within which this research study is embedded.

In our earlier discussion on the conceptualization of both primary and secondary stigma, it was highlighted that felt stigma and enacted stigma are the two commonest types of stigma and that these two can be experienced by both HIV/AIDS infected and affected people. According to Scrambler (1998) in Borgat, Cowgill, Kennedy, Ryan, Murphy, Elijah and Schuster (2007: 245): “Felt stigma is the fear of being discriminated against”.

On the other hand Borgat et al. (2007: 249) explain that enacted stigma has to do with actions directed at the infected person such as avoidance, insults, ostracism, violence and structural discrimination from health care institutions and employment organisations.

Several authors and researchers in the United States of America observe that HIV/AIDS related stigma is prevalent there and negatively affects people living with the disease as well as their families (Gostin and Weber 1998: 3-19). Children of parents infected with the virus or disease tend to be affected psychosocially and experience adjustment problems which manifest in delinquent behaviour. Furthermore, Murphy, Austin and Greenwell (in press) report in (Borgat et al. 2007: 244) that:

HIV infected mothers who report high levels of HIV-related stigma score significantly lower on measures of physical, psychological, and social functioning, and higher on measures of depression, compared to mothers who report low levels of HIV related stigma.

It would appear that secondary stigma comes about as a result of social processes informed by societal expectations, traditions and cultures in specific contexts. HIV/AIDS is a health related matter and consequently unlike the biomedical model and its reductionist ‘germ theory of disease, the social model of health, is ideally suited to give a perspective and insight into the link between HIV/AIDS, stigma and discrimination in society.

A brief discussion on the social model of health is therefore essential to highlight the link between health, the environment, culture and society. The social model of health’s approach is holistic and it recognizes that various factors determine the health of individuals and communities.

For instance health is defined in the World Health Organisation (WHO, 1986: 1) constitution of 1948 as:

A state of complete physical, social and mental well-being, and not merely the absence of disease or infirmity.

By putting together the physical, the social and the psychological aspects of human existence distinguishes the social model of health as more desirable to explain the concept 'Health' in a more inclusive way that recognizes that people have opinions, attitudes, norms, values, belief systems, traditions and cultural histories they cherish, into which their conception of 'health' relates to.

Don Nutbeam (1998: 351) explains that:

Within the context of health promotion, health has been considered less as an abstract state and more as a means to an end which can be expressed in functional terms as a resource which permits people to lead an individually, socially and economically productive life. Health is a resource for everyday life, not the object of living. It is a positive concept emphasizing social and personal resources as well as physical capabilities.

For instance, many people in Africa, Asia, the Caribbean and the Pacific, practice their indigenous traditional or alternative medicine simultaneously with western medicine. In Sub-Saharan Africa, many people still consult the 'Sangoma' to sort out their health problems, in India the practice of 'Ayurvedic' medicine is still strong and yet still in China the practice of 'Acupuncture' does not seem to be giving way to modern western medicine. Therefore, the social model of health accommodates the fact that even before biomedicine; people had different perceptions and indigenous ways of coping with illness.

In Gerhardt (1995: 70), Thomas McKeown argues that "it was the social changes which made the major health impact of infectious diseases. In particular, he cited improvements in nutritional status, and better living conditions as key factors involved in limiting the impact of infectious disease. In the case of chronic and incurable health conditions, he argued for the importance of individual lifestyle decisions; he argued that personal behaviour is now becoming a predominant determinant of health.

The above is true if we have a closer look at factors such as industrialisation and rapid urbanisation and their spill-over effects that influenced drastic social changes from agrarian economies and modern economies.

As Giddens (2008: 267) states:

Illness has both personal and public dimensions. When we become ill not only do we experience pain, discomfort, confusion and other challenges, but others are affected as well.

Therefore, how sick human beings view themselves and are viewed by others and their interpretations thereof takes us back to the issue of human beliefs, norms, values, shared

meanings, cross participation and interaction with others. Stigma, whether primary or secondary, is therefore a by-product of belief systems inherent in a society.

In explaining secondary stigma against family members of people living with HIV/AIDS, Borgat et al. (2007: 250) explain that:

She said she told me that she's afraid for her daughter to be with me 'cause she doesn't know what I got from my mom. Another young child was rejected by a friend when he was younger: I told my friend and he told his parents and his parents never allowed him to talk to me anymore.

Irrational fears of contagion spark off this reaction to such an extent that caregivers and children are avoided by friends and other uninfected members of the extended family. It would seem that the initial feelings of stigma by parents with HIV/AIDS changes after receiving information and counseling about the disease and its routes of transmission as cited by Borgat et al. (2007: 250) below:

You know before I had this disease I looked at people badly. And it hurts for me to say. How could they do that? Why do they do that, sleeping around? My high and mighty standards, lo and behold, now I have the disease.

Borgat et al. (2007: 250) cites another infected person who used to look down upon the other infected people and those associated with them and described how her attitude changed upon learning about her own positive sero status:

...I found out that two of my friends had AIDS, I went ballistic over the whole AIDS epidemic...so, needless to say, he died and I never did go see him or nothing and then I found out I was HIV positive.

However, when majoring stigmatizing attitudes across countries and within the same countries, some studies found that there is variation in terms of the intensity of both felt and enacted stigma. For instance one study by Genberg, Hlakva, Konda, Maman, Chariyalertsak, Chingono, Mbwambo, Modiba, Van Rooyen and Celentano (2009) published these findings:

For example, one multi-site study found that HIV stigma was highest in Tanzania, followed by Thailand and Zimbabwe, and lowest in two South African sites when measured by a Negative Attitudes Scale; but highest in Zimbabwe followed by Tanzania and Soweto, South Africa and lowest in Thailand and Vulindlela, South Africa when stigma was measured by perceived discrimination and that these two scales correlated poorly.

Further research in Cambodia and Thailand conducted by (Knodel 2006; Knodel, Watkins, and VanLandingham 2003; VanLandingham, Im-em, and Saengtienchai 2005) found that while research participants reported some negative community attitudes and reactions, in some communities sympathetic and supportive reactions were much more common, with research participants reporting that neighbours showed caring feelings by visiting them and bringing them food and medicine. Educational programmes and campaigns increased the knowledge about HIV and have likely had a positive impact by alleviating fears about casual transmission, thus contributing to lower levels of stigma. Research in sub-Saharan Africa also reveals that in some communities members generally show moral and social support to those caring for people infected by HIV/AIDS (Chimwaza and Watkins 2004).

HIV/AIDS related secondary stigma is the theoretical framework on which this study is embedded and therefore emphasis on that aspect will be constantly highlighted to help keep focus of the core objectives of the study. Therefore, in lieu of the above stated facts as reported by the findings of previous research done in the United States of America, and in other countries such as Tanzania, Zimbabwe, Thailand and South Africa it would be interesting to see how the people of White City Jabavu in particular, would respond to the whole notion about secondary stigma and how it affects them as a result of their association with people living with HIV/AIDS. What makes the issue of secondary stigma in White City Jabavu even more disquieting is the fact that the South African government has spent large sums of money and other resources in programmatic efforts to educate the public on the facts around HIV/AIDS and its transmission modes and yet it seems these efforts have not borne fruit as people still unnecessarily stigmatize others. Now let us look at how South African academics explain the concept of HIV/AIDS related stigma.

## **2.5 ACADEMIC EXPLANATIONS OF AIDS STIGMA IN SOUTH AFRICA**

Refinements and elaborations have been made on Goffman's original definition and a lot of work done to show the impact of stigma on the lives of the infected and affected. However, it is apparent that even though internationally there is published evidence on HIV/AIDS secondary stigma, most research and literature is on primary stigma. HIV/AIDS secondary

stigma in South Africa is also very little considering the fact that it is one of the countries with very high prevalence levels in the world. Therefore, in trying to fill up the gap on local research and literature about secondary stigma, it would be appropriate to first start by looking at the current views of some of the South African authors and academics about HIV/AIDS. Views and research findings pertaining to HIV/AIDS are many but they can be grouped broadly under the following themes: sexual promiscuity, social death, pollution, witchcraft, religious and ancestral beliefs, as well as denialism. The latter aspect was the subject of heated public debates which will be discussed later in this paper but for now a look will be made at how some academics explain resuscitated traditional African beliefs as being discriminatory against women and creating a false perception that through their sexual promiscuity they are mainly responsible for spreading HIV/AIDS.

Let us consider Leclerc-Madlala's observation (2001: 533) of this phenomenon as cited in Deacon et al. (2005: 58), Leclerc-Madlala's argument is that there is a political dimension spiced by gendered popular understandings of and responses to the HIV/AIDS epidemic in South Africa, and that this will affect the strength with which people hold the belief:

The growing popularity of virginity testing [in KwaZulu Natal must be understood] within a gendered meaning-making process consistent with commonly held beliefs that the epidemic is the result of women being sexually 'out of control' ... virginity testing is an attempt to manage the epidemic by exerting greater control over women and their sexuality. In addition, virginity testing of girls helps to draw attention away from the role of men in the maturing epidemic, consideration of which has been conspicuously absent in the popular discourse on AIDS at all levels of South African society.

Reinforcing Leclerc-Madlala's point is the observation made and stated by Campbell et al. (2005) in Deacon et al. (2005: 58) when he asserts that:

Stigmatization of PLWA is part and parcel of a conservative reassertion of power relations of gender and generation and a public reinforcement of the social institutions whose moral authority rested on their ability to control the sexuality of women and young people (or at least be seen to control this sexuality at the level of rhetoric, if not at the level of reality, in the pre-AIDS days when it was easier for sexual 'transgressors' to be discreet about their activities).

Discrimination related to HIV/AIDS stigma is another worrying aspect that serves to hamper progress in the fight against this epidemic. Deacon et al. (2005: 4) state that although research on HIV/AIDS stigma has been done in the recent past in South Africa:

...it is important to understand HIV/AIDS stigma in relation to the broader social, political, economic and cultural context, and to address stigma as one of a number of causes of discrimination, reluctance to test, therapeutic non-compliance, and so on.

Apart from (Deacon et al. 2005), other prominent academic debates include recent work in South Africa on stigma by Posel (2004), Kalichman and Simbayi (2003, 2004), Patient and Orr (2003), Policy project (2003a), Stein (2003), Shisana and Simbayi (2002), Jennings et al. (2002), Niehaus (2007), Ashforth (1998,2000), Delius and Glaser (2005), Knox (2008) and other authors.

In particular, Patient and Orr (2003) cited in Deacon, Stephney and Prosalendis (2005: 26), suggest that a series of shared beliefs underlie much of the stigma against people living with HIV/AIDS (PLHA's) in Southern Africa. These beliefs are often unconscious and contradictory, but help to justify and create discriminatory behaviour against PLHA's. They are as follows:

- (1) 'If you have HIV you're going to die, I won't invest resources in you' (AIDS=Death).
- (2) 'HIV/AIDS is a punishment for sin' (AIDS = Sex = Sin).
- (3) 'We cannot change the way we do things – for example, condoms challenge cultural norms about procreation, and culture and tradition cannot be challenged' (AIDS = Condoms = Contraception = Cultural taboo).

Isak Niehaus (2007) on the other hand, in his research done in the rural community of Bushbuckridge, in Mpumalanga province, raises the concern about HIV/Aids infected people dying a social death before their actual physical death. This comes as a result of stigma which translates into the isolation of the patient by some close family members, friends and the family at large. The disruption of interpersonal relationships leaves the infected person without a solid support system for later on when HIV turns into full-blown AIDS. They then become weakened, tire easily, rapidly lose weight, develop acute diarrhea and sometimes lose the use of their legs and are therefore rendered immobile as they have to rely on other people to provide them with their most basic needs like food and water, as well as to clean them up whenever they have soiled themselves.

Ashforth (1998, 2000) highlights HIV/AIDS related witchcraft assertions as a manifestation of a traditional system that is undergoing change and in the process a vacuum is filled in by

feelings of anxiety, uncertainty and spiritual insecurity, in seeking explanation for the affliction.

Ashforth (2001: 3) explains that:

Cultural and religious traditions can make it difficult or impossible to openly discuss sexual practices in order to facilitate condom use. The subordinate status of women makes it difficult for them to practice safe sex while being vulnerable to rape and physical abuse. Norms of masculine sexuality encourage multiple sexual partners. Indeed, poverty itself entrenches habits and outlooks—such as the exchange of sex for money or the sense that life is short and risky, AIDS or no AIDS—that can make the message of safer sex extremely hard to sell.

Delius and Glaser (2005) talk about pollution as a result of a sexual encounter with an unclean person who did not undergo the traditional cleansing rites. A man becomes polluted when he sleeps with a pregnant woman a menstruating woman, a woman who committed abortion and a recently widowed woman who is still going through the traditional mourning rites.

Delius and Glaser (2005) refer to Schapera (1940: 194-195) who states that:

Sexual intercourse with such people would result in sickness, some other misfortune and even death. A woman was 'hot' during her menstrual periods, during pregnancy (especially during the early stages) and immediately after childbirth or aborting; widows and widowers were also 'hot' for about a year after their initial bereavement and both men and women were 'hot' immediately after intercourse.

Without appropriate traditional treatment, death becomes inevitable and therefore the relationship between sexual transgression, pollution and delayed death makes HIV/AIDS a fearsome catalyst of stigma.

Peter Knox on the other hand looks at the multifaceted response to HIV/AIDS by both the infected and the afflicted. His approach is that of African people who use traditional medicines to help limit the damage inflicted by the virus and yet on a spiritual level undergo rituals of reconciliation and social healing hoping that in the event of their death they will be reunited with their ancestors and therefore, get some sense of comfort. Knox (2008: 25) elaborates that:

Through a better understanding of the ancestor cult, Christian ministers could perform a more person-sensitive and culturally-adapted celebration of the sacraments of reconciliation and of the sick. These sacraments should minister to an individual's wellbeing of soul in relation to God, but also to the person as inseparably part of his or her society.

These academic debates are important in providing thematic categories in the analysis of primary stigma directed at the infected individuals but leave very little explanation as to the impact of secondary stigma on people associated with the infected people. In other words there is a wide gap in terms of knowledge and research directed at understanding the phenomenon of secondary stigma as related to HIV/AIDS. However, it is the aim of this research study to attempt to minimize that gap by analyzing the opinions and experiences of people who endure secondary stigma as a result of being associated with HIV/AIDS infected people.

## **2.6 PUBLIC DEBATES ON HIV/AIDS IN SOUTH AFRICA**

Besides academic debates there are other people whose voices have been louder and thus dominated the public discourses on HIV/AIDS in South Africa. These people are the former President Thabo Mbeki, the former minister of Health Dr Manto Tshabalala-Msimang and Zachie Achmat an HIV/AIDS activist. Imagine the impact of the views of the former Head of State Thabo Mbeki, the former Health Minister Dr Tshabalala-Msimang and Zachie Achmat of the Treatment Action Campaign, in influencing public opinion and health policies in response to the HIV/AIDS pandemic. Dr Tshabalala-Msimang regularly encouraged the infected people to eat healthily and to include in their daily meals garlic, beetroot, lemon and ginger as substitutes for antiretroviral drugs needed to boost the compromised immune system.

The racist colonial stereotypical view of an African was that of a lazy, thieving and very promiscuous soul. This set the tone of stigmatizing the African as being immoral and promiscuous. A visit to this sex stereotype in relation to the HIV/AIDS calamity in South Africa was evidenced by the denialist attitude of the former President Thabo Mbeki when he questioned the causal link between HIV and AIDS.

Jackson (2000: 6) explains:

In 1999/2000, President Thabo Mbeki of South Africa gave the so-called 'dissident' view considerable support, blocking the use of drugs to prevent HIV transmission from mothers to their babies and, without intending to, undermining other prevention efforts. Undoubtedly this has led to many more HIV infections in babies in South Africa that could have been avoided, and to increased sexual transmission.

It looks like former President Mbeki was reacting to the age-old colonial view that Africans are by nature promiscuous and his denial affected prevention efforts and gave a false sense of security to people who were already infected by HIV/AIDS. However, to his credit, President Mbeki seems to have been misunderstood, as he was merely articulating the fact that the treatment of the disease cannot be separated from poverty issues because poverty and lack of good nutrition speeded up the progression of HIV to AIDS. One of his major concerns was that, how do you give free anti-retrovirals to someone who has nothing to eat because he/she must first fill-up the stomach before ingesting the treatment!

However, HIV/AIDS treatment activists such as Zachie Achmat of the 'Treatment Action Campaign', a non-governmental organization opposed Mbeki's views and essentially supported the biomedical view that HIV/AIDS is caused by a sexually transmitted virus. He also supported the recommended scientific approach of treating the virus with anti-retroviral to delay the onset of the full blown AIDS stage. He eventually won the court case after referral to the Constitutional Court, for the free supply of 'Anti retroviral Drugs' (ARV's) by the government of South Africa at all public health institutions throughout the country.

This after more than 350 000 people had died of HIV/AIDS related diseases due to lack of access to antiretrovirals that could have prolonged their lives.

The Lancet Journal, editorial (2005: 546) captures the then South African government's attitude towards the HIV/AIDS crisis this way:

Social stigma associated with HIV/AIDS, tacitly perpetuated by the Government's reluctance to bring the crisis out in the open and face it head on, prevents many from speaking out about causes of illness and deaths of loved ones and leads doctors to record uncontroversial diagnoses on death certificates. Earlier this year, Nelson Mandela stepped into the limelight and was widely praised and admired for openly attributing the death of his son Makgatho aged 54 years to AIDS just hours after he had died. To change attitudes, many more such disclosures from respected public figures are needed in a country that has more than 5 million people who are HIV positive....The South African Government needs to stop being defensive and show backbone and courage to acknowledge and seriously tackle the HIV/AIDS crisis of its people.

This statement shows beyond any doubt that the government's indecisive response to the treatment of HIV/AIDS is one of the public discourses that encouraged the stigmatization of the disease itself, the infected as well as the affected people.

## 2.7 CONCLUSION

Considering the theoretical framework, literature review and all the discussions and views on HIV/AIDS, its proliferation and resultant stigma, it is apparent that some aspects in the discussion are based on facts considering the historical structural violence of the apartheid system on Black people. Nevertheless, there are still a lot of myths and ignorance surrounding this disease. Opinions and theories vary from political economy, to conspiracy theories, to moral and socio-cultural-religious beliefs that are translated into action and public discourse. Issues' pertaining to secondary stigma in South Africa need to be addressed as a matter of urgency and one way of doing it is to build a reliable literature based on research conducted on this topic. All dimensions of stigma must be uprooted or rather minimized if we are to survive and reverse the damage done by this disease which in any case has the propensity to annihilate a large part of our population if it is not stopped.

What is also needed are effective stigma reduction strategies and the method that should be used is the bottom-top approach. Stigma and discrimination are characterized by cross cultural diversity and complexity which is one of the factors that limit the understanding of HIV related stigma. To make serious progress in analyzing and responding to these phenomena it may be necessary to attend to their cross cultural complexity as well as rethinking some of the frameworks that are granted them (Parker and Aggleton (2003).

Furthermore, especially within the African context where many people still cling to their traditional beliefs, the social model of health helps in giving insight and understanding of HIV/AIDS related stigma within the broader social, political, economic and cultural environments. Better informed public and highly sensitized health professionals can act as barriers against virulent cultural stereotypes likely to reduce the high rates of discrimination. Posel, Kahn and Walker, (2007) sum it well by explaining that, in doing so the mistrust and suspicion of health workers by ordinary people should also be taken into consideration and strategies developed to help curb this problem. Therefore HIV/AIDS related secondary stigma exists and seems to be a universal phenomenon that can be dealt with through appropriate culture sensitive strategies and educational methods geared to explain the sexual mode of HIV/AIDS transmission from one person to another.

## **CHAPTER 3**

### **BIOGRAPHICAL OUTLINES OF RESEARCH PARTICIPANTS**

### **3.1. INTRODUCTION**

This chapter lays the basis for the discussion of findings in the next chapter by introducing the key research participants who were identified by the ‘Soweto Home-Based Care’ NGO on behalf of the researcher. All the names used are pseudonyms to help protect the real identities of the research participants and all research participants interviewed are Black and comprise of eight males and seven females whose ages range from 34 years to 68 years. They are all fluent in the Sesotho language even though some of them belong to other ethnic groups such as the Northern Basotho, the Batswana, the BaNdawo of Mozambique and the Mashona of Zimbabwe. Interviews were conducted in the Sesotho and English languages and thereafter translations into English were made during the interview transcription phase. Most of the participants have passed standard ten and include a security guard, a motor mechanic, a Bachelor of Commerce (B. Comm.) graduate, a school teacher, a professional nurse, a librarian, a priest, an administrator, a sales representative, a community health worker, a qualified traditional healer, a domestic assistant, a medical doctor, a garment factory worker, a debt collector and a librarian.

Fourteen of the fifteen participants are not HIV/AIDS infected but they are key role players lending support to infected people – except for only one participant who is both HIV/AIDS infected and affected. All of them bear testimony to the scourge of secondary stigma in White City, Jabavu as all of them are touched by this kind of stigma as a result of their association with people who are infected. For instance in many cases these research participants recall being stigmatized and victimized because of their association with infected people. They are interesting people and the following are their short biographies.

### **3.2. BIOGRAPHICAL NARRATIVES**

#### **A) SPORO - WCJ O1 CM (Black Male)**

‘Sporo’ was born in 1972 in Ladybrand, in the Free State province but his family relocated to White City, Soweto in 1978. He started his primary school education in Soweto and completed his High School in that township where his parents still live. He is not yet married and has passed his standard 10 in 1991 but because jobs are very scarce and unemployment very high he resorted to accepting the lower-paying security job in order to be able to put bread on the table, after all as he says ‘half a loaf is better than no bread at all’.

From childhood he related very well to his family, friends and neighbours – in fact he could safely say that his family was very much well liked by all and his parents used to have a very large number of patrons at their house shebeen. They sold alcohol to the township folk to augment income and opening up their house as a ‘drinking spot’ made them well known and very popular with many people in White City.

Sporo recently lost a brother to HIV/AIDS.

#### **B) LEHLOHONOLO - WCJ 02 CM (Black Male)**

Lehlohonolo was born in 1950 into a Christian family on a farm in Walmansthall near Pretoria where his parents worked as farm laborers. His parents were also born and raised up on that farm because that is where their parents also worked. A new owner bought the farm and on restructuring, some of his laborers including Lehlohonolo’s parents were retrenched. In 1960 his parents relocated to White City - Jabavu in Soweto where he schooled and completed his standard 9. He soon had to find work in order to look after his unemployed parents and later on he learnt to be a car mechanic from his paternal uncle and still uses this skill to make a living.

Ever since then he and his parents have been relating very well with their neighbours and their extended family members even though many of them live very far away in the Limpopo province. His childhood years in White City were normal and he grew up playing soccer, bird hunting at Mofolo Park and fishing at the Kliprivier (Klip River). He also prided himself in proposing love to girls when he reached the age of fifteen and he succeeded many a time and thus his peers admired him for his courage and conquests. His closest friend Velaphi is HIV/AIDS positive, is still employed, looks healthy and takes regular treatment.

#### **C) MANTSOPA - WCJ 03 CM (Black Female)**

Mantsopa is 34 years old, was born in Maseru West and grew up in Lesotho for the first 11 years of her life. She is the first born of the two siblings in her family. Presently though for the past 10 years she has been based in White City Jabavu – living with her widowed and childless aunt who also originates from Lesotho. She thinks her relocation was a strategic move by her family because her aunt needed to be with someone but at the same time relocating to South Africa sort of opened a lot of doors for her in terms of employment opportunities. In Lesotho she was an unemployed university graduate with a Bachelor of Commerce (BComm) qualification but now she is employed, earns a decent salary, owns a

car and therefore she is highly mobile. Hence she goes at least once in three months to visit family in Lesotho.

As for the relationship with her parents, it is very good and she also feels she had a very good childhood and cannot even complain about their neighbours. She associated easily with her peer group as she was a very playful child. In Maseru West it was easy to interact with the neighbours because they lived in a government owned village compound and as a result they were forced to interact with each other. However, her family has since moved from Maseru West to a new location called Naledi and Mantsopa finds it difficult to associate with the new neighbours because she finds herself unable to make a lot of friends there and therefore tends to spend most of the time in the house when she is on vacation from South Africa. Generally speaking, her childhood was good – she enjoyed good relationships with family and friends.

She indicated that in Sesotho ‘Stigma’ which is the subject of this research is called ‘Sekhobo’- meaning a negative mark, very bad in nature and weighing heavily against the victim. Stigma or sekhobo usually becomes a lifelong burden as was the case with her late paternal aunt who succumbed to HIV/AIDS.

#### **D) PONTSHO - WCJ 04 CM (Black Female)**

Pontsho is a qualified English and Geography teacher who was born in Maseru West, Lesotho 50 years ago. Her father, a former government official, was in the habit of changing government jobs that made the family move from one place to another within Lesotho. Her father has always maintained his family tradition of supporting the then popular official opposition party and she thinks the Lesotho government got fed up with him and found a way of terminating his services and as a result lost not only his job but all the other accompanying benefits that included free government housing. During her father’s period of unemployment, her mother was the sole breadwinner and she never complained even for a single day – this goes to show how strong her family bonds are. She comes from a closely knit Christian family and hence when her uncle who owned a house in White City, Soweto passed away, the extended family decided that her father must relocate to Soweto in order to inherit his deceased brother’s house and also to be nearer more job opportunities in Johannesburg as he was unemployed for a long time in Lesotho. However, they arrived in White City when she was about 11 years old. She continued with her primary, high school and tertiary education in

South Africa and ever since then her father got employment in South Africa through the influence of some of their relatives who have been living longer in Soweto.

They get on very well with their neighbours, friends and the community at large and always cooperate by helping each other when there are weddings, funerals and other communal events around. In her neighbourhood everybody knows one another and they all protect and watch each others' backs against criminal elements.

On the job Pontsho is not only a teacher but also plays a counseling role to troubled pupils including those who are HIV/AIDS positive.

#### **E) MAMOKETE - WCJ 05 CM (Black Female)**

Mamokete is a 54 year old divorcee who came back to live in White City in the house which was originally her late paternal grandmother's. After her divorce she left her house in Diepkloof extension a very posh township of Soweto because she had bad memories of her marriage. Therefore, she later opted for the sale of the house and thereafter shared the money as well as everything else equally with her husband. They did not have children after 18 years of marriage because of a rare biological condition that is afflicting her. Her husband and her in-laws never took kindly to the fact that she could not give birth to their grandchildren after having paid 'lobola' (dowry) for her.

They encouraged her husband to marry a second wife and he brought that suggestion to Mamokete but she did not like the idea for fear of being humiliated in case the second wife bore children. Therefore she opted for a divorce because the husband always insisted that he wanted to marry again and have children.

Other than that she enjoyed a very good relationship with her parents, siblings, friends, colleagues and neighbours from her childhood years up to the present.

Mamokete is a nurse by profession and comes across many people afflicted by HIV/AIDS. On a number of occasions she used her house as a temporary sanctuary for infected individuals who were being rejected by their own families for fear of passing on their infection to them.

**F) SEKHOTHU - WCJ 06 CM (Black Male)**

Sekhothu was born and brought up in Orlando East in Soweto in 1956. His father was 91 years old when he passed away and his mother was 93 years old. Sekhothu is a priest of the Anglican Church in the diocese of the Church of the Province of Southern Africa and he is the second son amongst nine girls. Sekhothu started living in White City in 1989 and the house he occupies used to belong to his maternal grandmother.

Despite the fact that theirs is a big family, his childhood years are full of fond loving memories they share as a family. They are a close knit family and his relationship with his parents and siblings was and is still fantastic. Together with his siblings they relate well to each other and even share personal secrets. He also enjoyed a profoundly good relationship with his neighbours, childhood friends, school friends and other school mates.

Sekhothu comes across many in his congregation who are infected and affected by HIV/AIDS and often seek his spiritual guidance and moral support. Quite often he mediates in family disputes where one member is being victimized by the others for being HIV/AIDS positive.

**G) TSHEPE - WCJ 07 CM (Black Male)**

Tshepe was born in the Leribe district of Lesotho at a village called Ha Qokolo in 1948.

He obtained his standard 10 certificate through private correspondence with Damelin college and is presently employed as an administrator by the Johannesburg City Council.

Back in Lesotho, Tshepe grew up herding his father's cattle, sheep, goats, donkeys, horses and tending the fields. You can imagine that these are very demanding tasks that had to be coordinated with one's peer group members who also had to perform such duties in their families. So he enjoyed his childhood years looking after cattle in the grazing fields and stalking birds and catching field mice. As shepherds they also ate wild berries, water melons, fried maize and pumpkins that they took by stealth from the nearby farms. Tshepe used to be the champion amongst his peer group when it came to stick fighting – he could defeat all three guys at once in a stick fight.

He enjoyed a very strong and special relationship with his late parents. His mother was the eldest wife of his father who had four other wives. Apparently his mother was his father's favourite wife and this aroused jealousy in the other wives who plotted to have Tshepe and

his mother evicted from their family property should the father somehow become physically disabled or pass away. So in 1965 when his parents got ill and passed away one after the other, on the same day, poisoning was suspected by the Chief and the village people but forensic tests and evidence in the then rural Lesotho could not be made available as it was too expensive. Fortunately for Tshepe, his uncle who lives and works in Gauteng took him back with to South Africa because he feared that he could also die a mysterious death like his parents. So through his connections in Johannesburg he organized official papers for him to stay in the city.

Drawing on a deep breath, Tshepe reminisces and indicates that back in Lesotho it was non-negotiable as all children had to respect their neighbours and elders. Therefore he got along very well with everybody and because of his popularity their village Chief and elders had earmarked him to play a very senior and important role in the affairs of the village when he came of age. Unfortunately that did not happen but Tshepe still enjoys good relationships with his family, neighbours, friends, colleagues and many other people in Soweto.

Tshepe and his wife have been living in their house with his wife's nephew who is HIV/AIDS positive for the past three years. The nephew was rejected by his immediate family for fear of contaminating them.

#### **H) DAYOFF - WCJ 08 CM (Black Male)**

Dayoff was born and bred in Pietersburg 40 years ago but has been living in White City for the past 25 years. He is a university drop-out but is presently employed as a regional sales representative by a leading beer distilling company in Johannesburg. His parents are now deceased. His childhood years were good and he related very well to his family, friends and neighbours.

David's beloved sister-in-law passed away as a result of HIV/AIDS.

#### **I) MARIA - WCJ 09 CM (Black Female)**

She was born in White City in 1954 and she is the eldest of 3 sisters. She is a community health worker with the Gauteng Provincial Health Department. She was never married and she is also a self-employed dress-maker. She has two children a 28 year old boy and a 25 year old girl. Both of them have completed their university studies and are now married and stay with their spouses in their own townhouses in the northern suburbs of Johannesburg. Both her

parents are deceased and presently she lives with her late sister's three children who are aged 10, 15 and 19 years. She is their legal guardian now and started playing that role after her sister succumbed to HIV/AIDS which she got from her husband who passed away 6 months before her wife's death.

Maria always enjoyed very good relations with everybody as she appears to be that friendly and likeable type of a person. Her family liked her a lot and all her neighbours from her childhood days up to the present day have never complained to anyone about her. As for friends, she has many and she is also a diehard supporter of 'Kaizer Chiefs Football Club'. She is very sociable and likes hosting parties and inviting supporters of the 'Kaizer Chiefs Football Club' to her house parties. Apparently she at least has such a supporter's party once in three months.

Maria lost a sister and a brother-in-law who died of HIV/AIDS related causes.

**J) TAUHADI EA MATSHEKHA - WCJ 10 CM (Black female)**

Maggie is 68 years old but looks 10 years younger than her age. She is a qualified Sangoma (traditional healer) with a well known and good reputation for helping sick people including those afflicted by HIV/AIDS. She is the 7<sup>th</sup> child in a family of 6 daughters and 4 sons and she was born and raised up in a small dorp (little town) called Jagersfontein in the Free State province. Her parents were both of the Batswana extraction. The family relocated to Soweto in search of better economic prospects way back in 1948 when most of these Soweto townships were still informal settlements made up of corrugated iron and known as Shantytown or Masakeng. Her parents patiently worked hard until they got a proper house of their own. Nevertheless, she grew up being a very sickly child and no clinic, hospital or doctor could determine what was wrong with her. Anyway, she enjoyed a very good relationship with her parents, neighbours and childhood friends even though she was seldom outdoors playing due to her ill-health.

She is a popular traditional healer who also treats many clients who are HIV/AIDS positive and can testify to the social injustices endured by some of them.

**K) MPHATLALATSANE - WCJ 11 CM (Black Male)**

Mphatlalatsane is a domestic assistant employed by one of the rich families living in one of the other townships of Soweto. He was born in the Masvingo province of Zimbabwe in 1962

and both his parents are still alive and trying to make ends meet despite the negative political, economic and social climate in Zimbabwe. His father is Ndebele by birth and his mother Shona by birth and therefore according to the patrilineal custom and tradition he is a Zimbabwean of Ndebele heritage. The Ndebele's never forget their South African roots which can be traced back to one of King Shaka ka Zulu's popular army general, Mzilikazi. Mphatlalatsane actually grew up in an extended family set-up as part of his paternal grandparents' household with 17 people living and cooperating a lot financially, in terms of doing household chores, with women and girls tending the family fields and the boys looking after cattle and other livestock. So their family was very much united and he enjoyed his childhood a lot playing around with children of the neighbourhood in the surrounding hills and valleys and he does not remember any adult person, male or female ever ill-treating them or saying bad things to them at any stage.

Mphatlalatsane relocated to South Africa 8 years ago due to the economic hardships in his country and now has a South African green identity document but still his accent gives him away most of the time because it is not South African. He complains that his black skin is of a darker shade and therefore adds to the fact that he finds himself being stigmatized by some locals who look down upon Black people like him as unwelcome foreigners and yet there are a lot of other White foreigners from the former Eastern bloc communist countries that have relocated to South Africa but are never called names. He cites the case of the Chinese people that have been officially reclassified as 'Black' in South Africa after their appeal against originally being classified as White and thereby discriminated against when it comes to giving business tenders to Black owned companies in compliance with the present government's Black Economic Empowerment (BEE) policy.

Mphatlalatsane accuses South Africans of being generally xenophobic and using derogatory names to refer to them foreigners as 'amakwerekwere' who steal their women and jobs and cited the xenophobic violence that happened on the East Rand and in Alexandra township in February 2008 where many 'Black foreigners' were displaced and even killed by the locals.

Mphatlalatsane has an HIV/AIDS positive friend for whom he took the responsibility of caring for after having been rejected by many people including the landlord who threw him out of his yard as soon as he became weak due to his lowered immune system.

#### **L) MASIA - WCJ 12 CM (Black Male)**

Masia is South Sotho speaking and is a graduate of the University of the Witwatersrand Medical School – he is a medical doctor by profession. He is the only son and the eldest of three siblings – he was born in 1956 and his father skipped the country and went into exile in 1963 as a member of the then outlawed African national Congress (ANC). They were literally raised up by their dearest and hardworking mother who sacrificed so many things for their sake. He is not bitter though against his father for having left them when they were so young and vulnerable. The father came back from exile in 1992 and has ever since then tried to make up for the lost time between him and his family. He says he does not know where his dear ‘Papa’ got the money from but on his return he bought a very nice house in suburban Johannesburg for himself and their mother and also bought each one of the children a nice house in a suburb of their own choice. He added to that extravaganza by again buying each one of the children a motor car. Masia concluded by saying that his relationship with his father, mother and siblings is good and he thinks being the only boy amongst the girls spoils him with love and attention. Masia enjoys a good relationship with his family, neighbours and friends and pays special gratitude to the neighbours and friends who helped to shelter them during their father’s absence. He can safely say that he also had a wonderful relationship with his school friends, teachers and everyone else at school.

As a medical doctor, Masia has clients who are infected and affected by HIV/AIDS and their plight often touches him and arouses some sad emotions.

#### **M) TATIBI - WCJ 13 CM (Black Female)**

Tatibi is a garment factory worker employed by a prominent clothing manufacturing company which supplies popular brand labels to up market retail clothing stores in Johannesburg and the whole of Southern Africa. She has been living in White City for 20 years now.

She was born 53 years ago in Pimville, Soweto and both her parents are still alive, very strong and still live in Pimville.

She says she had a very easy and enjoyable childhood with a lot of friends in the neighbourhood, at school, in the church and everywhere else she came across people. She grew up loving the outdoors and being very vibrant and highly sociable. The relationship with her parents was also very good as she is an only child so there was no sibling rivalry for

her parent's attention. She is a single mother of twins (boys) and she divorced their father about 9 years ago because of his adulterous behavior philandering with 19 year and 20 year olds. She says her sons are now nearer completing their tertiary studies and they will probably be done in a year or two.

Tatibi cooks, cleans and cares for her elderly next door neighbour whose is also stuck up with an HIV/AIDS positive daughter who returned from her marital home after her husband died.

#### **N) TACASH - WCJ 14 CM (Black Male)**

Tacash is a 58 year old debt collector employed by a well known furniture company. He was born in Western Native Township next to Sophiatown and both his deceased parents originated from Lesotho where they were born and bred. His highest qualification is a standard 10 certificate and he is the second born child amongst four siblings. He has an elder sister, a younger brother and two younger sisters. He enjoyed a good relationship with his parents and siblings as well as with their neighbours and his childhood friends. He is of athletic built and he used to be a boxer and a marathon runner earlier on in his day.

He is proud that he was very popular with the girls, teachers and almost everyone else except for some boys who felt that he was over-rated with all the attention he was receiving from the girls.

He recently lost a friend who succumbed to HIV/AIDS.

#### **0) ELISABETHA - WCJ 15 CM (Black Female)**

Elisabetha has been unemployed for the past 7 years – she is a qualified librarian and has a Bachelors Degree in library science from the University of Limpopo, formerly known as the University of the North or Turfloop. She used to be employed by a big multinational company based in Johannesburg before she was retrenched due to ill health – specifically due to her HIV/AIDS positive status as she was becoming regularly absent from work because of her regular appointments with her doctor. She says she made the mistake of divulging her sero-positive status to her line-manager who recommended that she must be laid off but with a very good severance package.

She grew up in White City and her father passed away in 2002 and her mother is still alive and is a pensioner. She was born in 1962 and the third child in a family of five children, four girls and a boy. The other siblings are married whereas she was never married nor does she

entertain any marriage hopes for the future. Their only brother Simon is the last born of the family and he is also married and has his own house in the West Rand.

Elisabetha's family is apparently very close and members are very fond of each other. They share everything including personal secrets and they have been a peace loving family and as she says 'even our neighbours can tell you that truth'. She grew up being a very playful child – more of a 'Tom boy' than anything else and she had a lot of neighbourhood and school friends both girls and boys. Even at University and at her former place of employment she had many male and female friends and they got along very well to such an extent that they often came to visit her over weekends at her home even though the house is very small. At night they squeezed together on her tiny bed and had a good time chatting about this and about that before they fell all asleep.

### **3.3. CONCLUSION**

The above cited research participants are interesting people who come from very diverse backgrounds and thus volunteered a lot of information on their personal experiences with secondary stigma. In the following chapter a data analysis discussion will take place whereby they will be afforded an opportunity to be directly quoted on their opinions and experiences in relation to HIV/AIDS related secondary stigma in White City and also on issues that help to perpetuate and sustain that stigma.

## **CHAPTER 4**

### **RESEARCH FINDINGS AND DATA ANALYSIS**

## **4.1 INTRODUCTION**

This chapter is about the lived experiences of the 15 research participant in relation to secondary stigma in White City, Jabavu.

Some of their views are quoted verbatim, discussed and analysed in the light of the central themes developed in the literature review; namely: 'poverty and unemployment, immorality and sexual promiscuity, social death, ancestral beliefs and witchcraft, rejection and isolation, religious beliefs and denialism' to name but a few. Opinions, comments and expressions with a similar underlying message are identified and grouped together as common sub-thematic expressions under an umbrella theme.

Nevertheless, to make sense out of the various themes developed in the literature review as well as those themes that emerged from the fieldwork, it would be proper to make a brief analysis of the socio-economic background of White City within which secondary stigma exists. As mentioned in chapter one under the methodology and presentation of data discussion, where there is lack of evidence and support from the literature review chapter, reference to other academics not mentioned in the literature review section but coming from the broader literature on the HIV/AIDS subject will be made in order to facilitate a worthwhile discussion rather than not to engage in any discussion at all.

## **4.2 WHITE CITY AS AN ENVIRONMENT OF STIGMATIZATION**

As illustrated in chapter 1 - White City is a community with a history and culture of stigmatization and therefore it is inclined to be more stigmatizing. As a result, HIV/AIDS occurs in an already pre-existing environment of stigma. The various themes emerging from the fieldwork data are not mutually exclusive nor mutually exhaustive but nevertheless seem to confirm that the underlying cause for the HIV/AIDS prevalence levels and its associated primary and secondary stigmas come about as a result of unfavourable socio-economic conditions in White City. It is important at this stage to re-emphasize the fact that it is very difficult in a study of this nature to mention secondary stigma without mentioning primary stigma. The two are interrelated as one feeds on the other because there could be no secondary stigma without primary stigma and therefore the nuances around secondary stigma will constantly mention to primary stigma as a point of reference. Nevertheless, the core

business of this research study is HIV/AIDS related secondary stigma and therefore every effort will be made to focus on secondary stigma.

Therefore, it would seem that HIV/AIDS makes people adopt the traditionally unAfrican ways of relating to one another considering the bad treatment meted out against those who are infected and their families.

My study asked the question: ‘What is the nature of HIV/AIDS secondary stigma in White City, Jabavu’? Now this is the data that answers that question.

### **Multifactorial Causes of Stigma in White City**

It would seem HIV/AIDS stigma in White City is a complex issue that is precipitated by many underlying factors.

Research participants cited many reasons for acquiring HIV/AIDS and some of the themes that came up were poverty and unemployment, the wrath of ancestors, the wrath of God and ‘isidliso’. This ‘isidliso’ is some form of bewitchment as a result of black poison being spiked on one’s food by witches or alternatively sent in a dream form. Someone dreams of having a nice meal and in the process of enjoying the meal she unknowingly swallows this ‘isidliso’ which later on creates serious health problems leading up to death if the diagnoses and treatment are not done properly by consulting a traditional healer. Now let us look at what some respondents had to say about the influence of poverty and unemployment over the spread of HIV/AIDS and its related secondary stigma.

### **Poverty and Unemployment**

Poverty and Unemployment is a theme in absolute agreement with the literature review as a contributory factor towards the proliferation of HIV/AIDS and its resultant secondary stigma. Poverty and unemployment are a major overarching theme that persistently emerged from the fieldwork and both these phenomena were strongly identified by research participants as contributory factors that helped to destabilize many people’s lives as well as help with the acceleration of the proliferation of HIV/AIDS and its related stigma in White City Jabavu.

As Morris (1980) puts it:

The broad determinants of the health status of a community are cultural, socio-economic and environmental.

This statement by Morris (1980) resonates very well with the social model of health which views the causes of illness as transcending the limiting 'germ theory' approach of the bio-medical model of health, discussed earlier in the literature review section of this study.

To rehash, in the bio-medical model of health illness is caused by minute organisms such as germs living outside the body, which are said to be responsible for causing infections and other illnesses when coming into contact with the body of a human being or an animal. On the other hand the social model of health compliments the bio-medical model of health by acknowledging the fact that illness and disease are caused by germs that thrive in an environment created by negative socio-economic factors such as unemployment and poverty among other factors.

The following views by some of the research participants will further help enrich and illuminate this discussion.

On being probed about the socio-economic conditions in White City Sporo observed:

Many people in White City are not so well educated and consequently there is a high unemployment rate and poverty is rife especially amongst the youth as compared to other people who live in middle class areas of Soweto such as Dube village, where many people of my parents age-group and my own age-group are working in professional occupations such as teaching, nursing, business managers, and so on. In White City if you are HIV/AIDS positive you are rejected by your own family because you become both a financial burden and an embarrassment in the community (Views of Sporo WCJ 01 CM).

Another respondent Lehlohonolo expressed himself this way:

White City Jabavu is a poor man's place as you can see the two and three roomed houses built in a congested space by the former apartheid authorities. Many people are unemployed and I just wonder how on earth the Matriculants of 2009 will ever find employment? Jobs are really scarce and can you believe when I tell you that some families of ten people rely on the monthly government pension money earned by the 'oldlady' (grandmother) of the house. Here in White City it seems like there is less people employed compared to those unemployed..... hey broer (brother)! The place is teeming with people even on normal week days the streets are full of multitudes (Views of Lehlohonolo WCJ 02 CM).

Pontsho, a professional and well respected teacher in the area had this to say:

Unemployment is very rife in White City and I am well placed as a teacher to see how many of our students at my school struggle to make ends meet – and I literally mean lacking in most basic things including school uniform, important text books and as far as I know up to 70% of the students cannot afford to pay the comparatively affordable school fees and our school relies heavily on government subsidies. It is very sad and a tragedy to see some of my students not having anything to eat during lunch time and the bolder ones would appeal to me to give them some money to buy food. (Views of Pontsho WCJ 04 CM)

All research participants agreed on the negative role played by poverty and unemployment in compromising the quality of the fabric of family integration, social cohesion and the health of individuals who engage in risky behavior as a survival strategy. It would seem that HIV/AIDS affected households are doubly disadvantaged as they experience a multiplicity of stigmas. Firstly, they experience the burden of secondary stigma and are rejected, isolated and treated with suspicion by some members of society. Secondly, some family members perpetuate primary stigma as they discriminate and ill-treat their infected family member because they view them as the cause of their exacerbated poverty because meager family resources now have to be redirected towards the treatment and care of the sick member.

The third aspect of stigma is a lack of access to a better life as a result of poverty and unemployment.

Structural issues keep on resurfacing to point out the role played by the previous apartheid authorities in creating and perpetuating the culture of stigma in Black townships such as White City.

Let us look at what some of the research participants had to say about the sexual practices of many young people in White City.

### **Multiple Concurrent Sexual Partnerships (MCSP)**

Linked to the above theme of Poverty and Unemployment is the theme of Multiple Concurrent Sexual Partnerships which consistently emerged during in-depth interviews with the participants. Therefore this theme on multiple concurrent sexual partnerships concurs with what has been written in the literature on this topic. Morris and Kretschmar (1997) explain that:

Modelling studies have illustrated that concurrent sexual partnerships result in sexual networks that have densely clustered pathways that do not occur when people have sequential relationships that do not overlap in time.

As we shall see many young people in White City are engaged in the risky practice of maintaining multiple concurrent sexual partners. Now let us look at what some of the research participants had to say about this kind of sexual practice in White City.

For Sporo his views were expressed this way:

A lot of young men engage in crime to acquire money and other desirables. On the other hand a lot of poor women are involved with older men who provide them with money and gifts in exchange for sex. These older men are popularly known as 'sugar daddies' and they are often of the same age as the young woman's mother or father. Having secret sexual liaisons with several of these sugar daddies who are often married family men simply means the young lady will receive more sources to tap into in order to access more money and gifts such as cellular phones, clothes and in some cases motor cars. Having many sexual partners will increase their chances of acquiring HIV/AIDS (Views of Sporo WCJ 01 CM).

On the other hand Lehlohonolo had this to say:

Unemployment is evil broer because you see many old women and young girls prostituting themselves in exchange of money. Wena (you) if you were in their place what could you do broer? I mean they have to live and survive as well as provide food for their 'illegitimate' children whose fathers are probably also unemployed and therefore are unable to pay for their maintenance (Views of Lehlohonolo WCJ 02 CM).

Pontsho who is a renowned school teacher with an excellent teaching track record and reputation had this to say:

Now, these ladies come from equally poor backgrounds and fall easy prey to these young men who are suddenly well to do and can afford to give money and other gifts to these materially deprived young ladies. It is really tough because many of these ladies engage in secret risky unprotected sexual intercourse with many of these young men in an effort to maximize their monetary gain. I think partly that is why we have so many HIV positive young ladies in White City. They are also carelessly spreading this disease by loosely sleeping around and you just watch how many funerals for the young ladies are there in one weekend in White City. I know of a family that lost three daughters in rapid succession as a result of this disease and in one street alone, more than 12 households have lost a member who died due to HIV/AIDS and this is besides those households who are caring for an infected member - Abuti (brother) it is really bad (Views of Pontsho WCJ 04 CM)!

Therefore, for whatever reason, promiscuous behavior plays a major role in the rapid proliferation of HIV/AIDS and it would seem that poverty and unemployment play a major role as well in influencing such behavior. It would not be far-fetched then to assert that

multiple concurrent sexual partnerships are a survival strategy whereby many unemployed and poor young women who are single parents become entrapped in to generate much needed income. It would seem that all the above themes are interrelated, with poverty and unemployment as the overarching feature, as one theme leads to another as we shall see in the next theme on alcohol and drug abuse.

Unfavourable socio-economic conditions are the breeding ground of disease and other social problems such as crime, prostitution, substance abuse and many others. In poor communities access to good health care is difficult and personal hygiene is sometimes compromised due to a lack of material resources. The scarcity of money and food tempts the young men to commit criminal activities and on the other hand also tempts the younger women to engage in transactional sex underlined by multiple concurrent sexual partners in order to survive. In other words, day to day survival issues like putting food on the table have precedence over more abstract moral and health issues stipulating the need to restrain sexual impulses in order to help avert acquiring HIV/AIDS.

Engaging in multiple concurrent sexual relationships is viewed by many practicing Christians as behavior lacking in morality which quite often is linked to a history of other behaviors such as premarital sex and sex outside of marriage as sanctified by God the creator. As a result many families of these teenagers suffer secondary stigma by virtue of association with the infected because they are also viewed as having failed in bringing up a decent law-abiding individual and therefore, the family is also viewed to be lacking in morality.

Now, let us have a look at the opinions of some of the research participants in relation to the role played by alcohol and drug abuse in perpetuating the spread of HIV/AIDS and its related primary and secondary stigma.

### **Alcohol and Drug Abuse**

The role played by alcohol and drug abuse in the proliferation of HIV/AIDS and its related primary and secondary stigma tallies with what is in the literature review. Interviews with research participants show that alcohol and drug abuse are common in White City and further contribute to the proliferation of HIV/AIDS as people engage in irresponsible sexual behavior when they are intoxicated. The following are the opinions of some research participants who observed the negative consequences of these substances.

A lot of these men and young women are unemployed but they seem to have unending reserves of money to buy alcohol and drugs such as ‘mandrax’ tablets, cocaine and others. I had always thought that maintaining the drug habit is very expensive but they have proven me wrong! After drinking alcohol and doing drugs these young people sleep with each other and ‘fuck each other as if tomorrow will never come’. How can we then get rid of HIV/AIDS (Views of Lehlohonolo WCJ 02).

However, alcohol abuse seems to be a syndrome prevalent not only amongst the young but even amongst parents themselves as one research participant Pontsho observed:

Hey, it has a really negative impact – you see many of my students are raised on their grandparents’ pensions, especially the grandmother. It would seem like many of their parents have since given up on finding employment, they just loiter around looking for places selling cheap African sorghum beer so that they can buy some and get drunk. It seems like they do not want to drink themselves into a stupor to avoid facing life’s challenges and realities. Nevertheless, what is important is that adultery is committed by those who after having a drink sleep around and some elderly women even sleep with any man who would buy them alcohol (Views of Pontsho WCJ 04 CM).

Therefore, the above statement further illustrates that alcohol and drugs affect decision making because an intoxicated person cannot think clearly and this results in some form of irresponsible behavior such as engaging in an unsafe sexual act with a younger person without using a condom or any form of contraception.

Most-at-risk populations (MARPs) are defined as those populations that are found to have a higher than average HIV prevalence when compared to the general population.

According to UNAIDS (2006):

MARPs engage in behaviours that put them at higher risk for HIV infection. At-risk populations are among the most marginalized and most likely to be stigmatized. In addition, resources and national HIV-prevention campaigns are not necessarily geared to their specific HIV prevention, treatment and care needs. In the generalized epidemics of southern African the definition of MARPs is not clear cut, as higher than average prevalence may apply to large populations and sub-populations. While some of these populations are not necessarily stigmatized or marginalized to the same extent as those subgroups falling into the international definition, it remains true that their risks are higher.

On the other hand since the men or rather the young men of White City, pay the bills for these alcoholic beverages and drugs as well as showering the young ladies with gifts, in return the young men have more say in terms of deciding whether to use a condom or not in a sexual liaison. Consequently, such reckless behavior also places the young men and women

of White City into the category of most at-risk people in terms of acquiring HIV/AIDS with its aftermath of primary and secondary stigma. This is a very unfortunate situation because substance abuse followed by 'flesh-on-flesh sex' as they call it carries a higher risk of HIV/AIDS infection more especially in consideration of the fact that many of these youngsters and of course some adults are engaged in multiple concurrent sexual partnerships. (Walker et al. (2004:71) explain that: "The sale of beer also offered opportunities for sexual liaisons".

This is often 'risky behaviour' underpinned by transactional sex with multiple-sexual partners and thus creating good conditions for the proliferation of HIV/AIDS.

Ankrah, (1991:971) further explains that:

..... Women become more vulnerable to HIV/AIDS because of their inferior position in society as compared to their men folk.

Young women are said to also engage in this sort of behaviour and consequently many of them have to later contend with unwanted pregnancies as well as being infected with HIV/AIDS as a result of alcohol and drug abuse. In the event of HIV/AIDS infection these young women are be tainted with the primary stigma of being infected as a result of their bad behavior and thereby setting a bad example for the up and coming girls and younger women. Consequently, their families suffer secondary stigma as a result of being perceived as morally lacking by bringing up such an 'immoral' daughter.

### **Crime and Gangsterism**

To help sustain an easy carefree life underpinned by the consumption of alcohol and drugs in a fun-filled environment where a number of sexual partners to choose from are easily available, many young men resort to criminal activities to secure money and gangsterism as a survival strategy in a hostile neighbourhood. Crime and Gangsterism are themes that also featured very strongly during in-depth interviews as seem to concur with the available literature linking HIV/AIDS proliferation to poverty, unemployment, multiple concurrent sexual partnerships as well as crime and gangsterism. The following are some of the views expressed by some respondents in terms of some social activities the young people engage in after acquiring money from their criminal activities:

Not to be outdone by the elderly men, the younger men popularly known as ‘amagents’ or the ‘clevers’, joined criminal gangsters for protection and to make a living and usually entice the younger women with spoils of their crime like stolen cellular phones, buying them beautiful fashion-label clothes, as well as riding in beautiful stolen cars and hopping from one tavern to another in pursuit of having a nice time. These young men are often not loyal to one sexual partner but maintain many sexual relationships with these young ladies and as a result become popular with their peers whose approval makes them feel proud about themselves and thus strive even more to maintain this ‘playboy’ image (Views of Sporo WCJ 01 CM).

Sporo’s views are supported by the views of Pontsho who articulates that:

As a result many of my students do not finish Standard Ten and the boys are quick to turn into crime and gangsterism – stealing motor vehicles, cloning them to sell to their buyers and normally these boys, commonly known as ‘amagents’ do not just steal or hijack somebody else’s car but do so in response to a specific request from a ‘client’. After getting money from the sale of these vehicles they buy themselves nice clothes, cellular phones and other fashionable items. They go to taverns and shebeens in beautiful German made vehicles, the favourites of which are Volkswagen Golf and BMW which are mostly clones of legally registered cars damaged beyond repair as a result of road accidents – with the help of corrupt traffic and vehicle registration officials who receive their bribes. At these taverns and shebeens they relax, flaunt their newly found wealth and have a nice time with the young ladies (Views of Pontsho WCJ 04 CM).

Now the term ‘amagents’ is the shortened version of the English word ‘gentlemen’ and is used interchangeably with the name ‘clever’ to refer to a streetwise township guy who normally survives on the proceeds of crime. Most of these guys have never been employed in their lives and even if they were, it was for a very short period of time, prior to resorting to criminal activities as a means of making plenty of money quickly.

Therefore, crime, gangsterism and poverty are two sides of the same coin as people strive to make a living out of the proceeds acquired illegally. The sudden availability of money acquired through criminal activities makes these young men feel like enticing and conquering any desperate woman willing to dance to their tune, even if it means practicing unprotected sex commonly known as ‘Dry Sex’. Crime and gangsterism themselves are socially inappropriate stigmatized behaviours and therefore an infected criminal gangster will suffer a multiple stigmas and unfortunately his family will not be spared the resultant secondary stigma because it will also be viewed as a morally lacking family.

### **Dry Sex - (Flesh-on-Flesh)**

Dry Sex or Flesh-on-Flesh is a phenomenon that has been identified by many researchers and authors on HIV/AIDS for its role in helping to spread the HI virus from one person to another. This phenomenon came also out strongly during in-depth interviews and concurs with the literature review as many men are reluctant to use a condom especially when engaging in a sexual act with their wives or trusted partners. In Southern Africa what many men have in common is the fact that they seem to enjoy having sex with a woman whose vagina is tight and dry because maximum friction in sexual encounter creates a more pleasurable experience for the man.

The following views expressed by two research participants Maria and Tatibi capture it all.

Maria said that:

The girls normally leech on these boys who seemingly always have vast sums of money with them wherever they go be it at our local taverns, shopping malls and everywhere. Poverty tempts these girls to sometimes exchange sex for money and other gifts. Ah! These girls have learnt to become sharks and any man, you (the researcher) included can fall prey to their snares regardless of their age (Views of Maria WCJ 09 CM).

Tatibi said that:

The rate of poverty and unemployment is very high here and that I can confidently tell you that a lot of girls around here are HIV/AIDS positive because they engage in unprotected sex with multiple partners in exchange for money, food and gifts. They even insert love potions inside the vagina to help make them more sexually attractive and satisfying (Views of Tatibi WCJ 13 CM).

However, further probing revealed that in many instances condom usage is deliberately ignored during sex because the woman wants the traditional love potion to rub off against the skin of the man so that it enters his body and makes him have 'eyes only for her'. This is a dangerous practice considering that some of these men are married men. On the other hand the unmarried younger men maintain a string of multiple concurrent sexual partnerships whereby they buy the services of commercial sex workers and also engage in transactional sex with local women who may transmit HIV/AIDS to them. In turn both these men and women risk infecting their wives and partners when they return to their homes more especially because the element of 'trust' and 'faithfulness' is said to carry more weight when

sex is engaged in without a condom, as they say 'flesh-on flesh'. The chances of transmission become high considering the abrasions, lacerations, lesions, cuts and so on caused by the elongation of the labia minora as well as the combined effect of corrosive substances being inserted regularly into the vagina.

Qualifying the above assertions, Scorgie (2009: 269) cites Berksinska et al. (1999: 179) as stating that:

In the context of HIV prevention, there are further ramifications: 'dry sex practices may be in direct contradiction to HIV prevention messages, which may include the use of lubricated male or female condoms, lubricants and microbicial creams or gels'.

Many African men also prefer a woman whose labia minora are elongated as the following statement by Rungana, Pitts and McMaster (1992: 1037), in a study of 30 men interviewed in Zimbabwe, qualifies the research findings:

...they specified a contracted, warm vagina as a desirable sexual characteristic.

This makes one observe how a woman and the vagina are traditionally and culturally symbolically conceived as the source of life, wealth, pleasure, wellness and good health. Many African women are engaged in vaginal practices whereby they use love potions and other substances to keep their vaginas tight and dry so as that male their sexual partners can view them favourably and want to have sex with them more often. The frequent the sexual encounter the more the money and gifts they receive in what one can refer to as the 'political economy of sex' as a means of survival.

However, it is noteworthy to mention that some research respondents mentioned that some women in White City use pure cold water to wash and help tighten their vaginas, others reported using 'Vicks vapour rub' ointment as a sexual stimulant when coming into contact with the skin and also due to its likeable aroma. On the other hand some women reported using acidic substances such as lemon juice to treat sexually transmitted infections (STIs) with the hope that the acidity will overpower and thus eliminate the sexually transmitted bacteria. On the other hand some women are reported to insert a mixture of love potions with salt and sugar added to tighten up their vaginas, with sugar meant to increase the sweetness of the woman during sexual contact, whilst others are said to insert snuff and brown wrapping paper to help 'dry' up their vaginas so that they are not too wet or watery and thus make a lot of noise to the irritation of their male partners who may not come back to them for more sex

in future. In the end when somebody has acquired HIV/AIDS, the resultant stigma goes beyond them and affects their closets associates like family and friends, who end up suffering secondary stigma because the sexual manner of transmission of the disease coupled with their proximity to the infected person renders them vulnerable to being also judged as morally lacking.

### **Lack of Good Nutrition**

In the literature of health and HIV/AIDS a balanced nutritious diet is very important in maintaining the good health of the infected person because it helps to prop up his or her compromised immune system. Therefore, it is also important to note that under impoverished socio-economic conditions where sexual promiscuity as a survival strategy co-exists with alcohol and drug abuse, it was not surprising to discover that no emphasis was placed on good nutrition as an important practice towards good health.

This theme on nutrition is in agreement with the literature review considering explanations by the medical personnel on the important role played by good nutrition in maintaining a balanced immune system. The former South African Minister of Health, Dr Manto Tshabalala-Msimang recognized this fact and hence she encouraged infected people to constantly eat certain kinds of food such as green vegetables, beetroot, garlic, lemon and other such nutritious foods.

In the interviews conducted four of the research participants highlighted the problem of nutrition and the first one is Mamokete who had this to say:

The impact is very negative indeed as HIV/AIDS related patients get very neglected by their own families who feel that in the midst of their poverty they now have to redirect their meager resources towards the care of their ill member. Whenever I hear about cases like that I usually refer them to social workers who after assessing the situation end up organizing either regular food parcels for the family or an alternative accommodation at a hospice or at a place of safety for the ill person (Views of Mamokete WCJ05 CM).

The second participant, Sekhothu was also even more elaborate and had this to say:

As a result of malnutrition many infected people die prematurely and on the other hand the diversion of the meager family resources to care for their sick causes too much tension and animosity within the family as other family members feel that it is unfair for them to carry the burden of someone who did not listen to sound advice but carried on leading a reckless lifestyle (Views of Sekhothu WCJ 06 CM).

Participant number three, Tshepe was also very vocal and explicit and said that:

Poverty and ill-health are two sides of the same coin because where there is poverty there is a whole range of socio-economic problems such as malnutrition, disease, crime, prostitution and other social ills. Look, let me be blunt, when people are hungry they are preoccupied with their hunger and think less of acquiring diseases such as HIV/AIDS. Therefore, a lot of young girls offer men sexual pleasure in exchange for money and other desirables and eventually this kind of carelessness is bound to create health problems such as a higher infection rate of sexually transmitted diseases such as syphilis, gonorrhoea and HIV/AIDS (Views of Tshepe WCJ 07 CM).

Participant number four, Dayoff expressed his views this way:

First of all HIV/AIDS is a disease that does not tolerate malnutrition – one has to eat but at the same time avoid junk foods and eat green vegetables, white meat and fish, eat a lot of fruit, drink a lot of water as well as do regular physical exercise. Therefore, a lot of the unemployed poor people do not enjoy the luxury of choosing what to eat or not, they eat what is available or offered to them otherwise they will starve to death. Therefore, considering the poverty around here and taking into account that a lot of the young men and women are infected - I think many of the infected do not have enough to eat let alone eating the recommended nutritious foods (Views of Dayoff WCJ 08 CM).

Poverty and more especially intergenerational poverty is a vicious cycle that serves to preserve the status quo and to perpetuate social inequalities that help to exclude other disadvantaged social groups and can be linked back to the political economy of the day.

### **Wrath of the Ancestors and God**

The wrath of the ancestors and God is a theme that confirms the literature review as it strongly cropped up in the in-depth interviews conducted.

In African culture ancestors are there to guide and protect their descendants and in turn the descendants must honour their ancestors by engaging in good behavior and by involving them in their lives. An African person who does not seek guidance and protection from the ancestors is said to be invoking their anger.

Yes my man – this is Africa and if you do not stick to your customs and traditions, the ancestors will be angry with you and give you HIV/AIDS to sort you out as you are no longer under their protection because you have adopted foreign cultures – the western culture. You now sleep around with ‘hot’ women, women who need to be cleansed and purified such as widows who have not finished at least one year of mourning, a woman who just committed an abortion, a menstruating woman and so on and so forth (Views of Tacash WCJ 14 CM).

On the other hand a closer inspection of the reasons for God's 'wrath' provided by some participants seems to be an indication that there is still a lot of ignorance, superstition, guilt, shame and blaming going around the subject of HIV/AIDS. Failure on the part of ancestors to intercede with God on behalf of the infected and affected, by bringing a miraculous cure, when traditional rituals are performed puzzles many African people who rely on their ancestors for guidance and protection. Self-blame and self-stigmatization seems to be a way of justifying punishment in this perceived helpless and hopeless situation. South Africa is a land of many religions but it is predominantly a Christian society to such an extent that traditional African beliefs co-exist alongside the Christian faith with its emphasis on the sacredness of sex and its accompanying sexual morality. Therefore, Peter Knox (2008) appeals to the Christian ministry to be more tolerant and understanding towards accommodating other indigenous belief systems by helping to integrate some of the local traditional beliefs such as ancestral worship into the mainstream Christian theology to help give Christianity an African flavor and context so as to make it easier, more appealing, more acceptable and sensible to the local African communities.

It is God's way of talking – of punishing sin. There is too much promiscuity around here even marriage is no longer a sacred institution as people just sleep around anyhow without boundaries anymore. In the olden days of our forefathers (ancestors) I hear that a married person would never sleep with an unmarried person, especially a teenager as people do nowadays. Today men sleep and father illegitimate children with girls fit to be their daughters – in a worst case scenario they commit incest with their daughters or alternatively impregnate their own daughters' friend/s. What do you call that Heh? Has the devil broken loose and is he now running amok? Yes HIV/AIDS is truly punishment from the Almighty for mankind's depraved morality...and what other better way to infiltrate the human body of a sinner and destroy it than through 'sex'- yes sex because people are being killed by what they love to do most - sex, sex, sex ...all the time. Yes HIV/AIDS is blood borne and there are a lot of dormant viruses living in our bodily fluids that are just waiting to pounce on us as soon as we stray from righteous ways (Views of Tatibi WCJ 13 CM).

On the other hand Lehlohonolo had this to say:

HIV/AIDS is caused by 'adultery' – too much cheating! People sleep around a lot and I think God uses sex to punish people who commit sin by sleeping around. Man, there is too much sin around here and people get killed for sex just because the other man desires to have sex with your wife or girlfriend then you will get killed. History repeats itself because even though I am not that educated but I remember the story of the man called Uriah in the bible – this man had a very beautiful wife and King David was desirous of the wife, then he made a plot with one of his army generals to put Uriah in the frontline on the battlefield so that he could get killed and therefore create a chance for King David to have sex with his wife without worrying about being discovered by the husband. My man this place stinks – as we talk right now

schoolgirls and everyone are fucking, fucking, fucking as if there is no tomorrow. I would equate these girls to prostitutes because they sell their bodies in exchange for money, food, clothes, cellular phones, alcohol and drugs and other material things (Views of Lehlohonolo WCJ 02 CM).

Peter Knox on the other hand looks at the multifaceted response to HIV/AIDS by both the infected and the afflicted. His approach is that of African people who use traditional medicines to help limit the damage inflicted by the virus and yet on a spiritual level undergo rituals of reconciliation and social healing hoping that in the event of their death they will be reunited with their ancestors and therefore, get some sense of comfort. Knox (2008: 25) goes on to explain that:

Through a better understanding of the ancestor cult, Christian ministers could perform a more person-sensitive and culturally-adapted celebration of the sacraments of reconciliation and of the sick. These sacraments should minister to an individual's wellbeing of soul in relation to God, but also to the person as inseparably part of his or her society.

Thus, the confluence of the practice of ancestor worship and Christianity makes one sensitive to the fact that health promotion messages must be designed in a manner that will also appeal to vast African audiences who still cling to their cultural beliefs and practices.

### **Witchcraft (isidliso)**

Witchcraft is a theme that strongly emerged from the in-depth interviews and reaffirms what is written in the literature review. The reasons for bewitching someone are many and diverse but in many cases witchcraft in the communities is elicited by jealousy, fighting over property or over some inheritance of some sort. Bewitching someone is usually viewed as an act of treachery and vengeful cowardice because the object of witchcraft might be physically, intellectually, financially, socially and politically too strong to challenge. In terms of witchcraft, infected individuals and their families suffer primary and secondary stigma not because people do not sympathize with them, nor because they were involved in any kind of socially unacceptable behaviour but because people do not want their 'bad luck' to rub on them.

Ironically, it is interesting to note that witchcraft is cited by a number of respondents as the source of their beloved's HIV/AIDS affliction and hence the consequent secondary stigma. Firstly, it is important to understand this dichotomy in terms of the indigenous African cultures. In African culture a bewitched person gets a lot of sympathies and understanding

from the community. Secondly, a bewitched person does not have to bear personal responsibility for his or her actions as witchcraft is viewed as being beyond one's control. Thirdly, families prefer to explain the infected individual's condition in terms of bewitchment because this makes it easier for them to deflect the social stigma associated with sexual promiscuity and HIV/AIDS.

Now let us see what some of the respondents had to say about witchcraft as the cause of HIV/AIDS.

Now this man just becomes ill and dies like that leaving me sick with a 16 month old baby girl – now apparently the mother-to-child transmission occurred at birth and the child is now receiving treatment together with the mother. You see upon my husband's death my family started accusing me of having killed their child by bewitching him. The allegation is that I spiked his food with 'isidliso or sejeso' which is black poison used by witches to kill someone very slowly and without any hard evidence before the law. So this man dies and I am evicted from my marital home without considering the fact that I am looking after our baby – I could not just fight back even legally because I just did not have the stamina to do so but the most scary part is that I was threatened by the husband's family that should I dare lay a charge with the police, then they are going to hire people to kill me (Views of Tatibi WCJ 13 CM).

On the other hand Ashforth (2004) states that HIV/AIDS has little resemblance to more "familiar" types of STD's. Symptoms of HIV/AIDS make it different from other common STI's and Ashforth (ibid) goes on to say that traditional healers have long interpreted the three main manifestations of AIDS in Africa as diarrhoea, tuberculosis, and wasting away and thus these symptoms are congruent to the symptoms exhibited by a person bewitched by means of 'isidliso'. In terms of witchcraft, 'isidliso' or 'black poison' can be poured into someone's drink or food and unknown to the victim they consume the drink or eat the food and thus become bewitched. Alternatively 'isidliso' can be sent by evil witches through magic to be eaten by someone in his or her sleep. What is also interesting is that although HIV/AIDS is incurable, many traditional healers view isidliso as curable. Ashforth (2004: 148) points out that:

A survey of South African healers generated a list of common isidliso- related symptoms, including weight loss, decreased appetite, coughing, vomiting (sometimes blood), and irregular heartbeat – many of which can be associated with AIDS.

Therefore, this is in line with the theoretical framework on witchcraft as a perceived source of HIV/AIDS and its related stigma.

Ashforth also highlights HIV/AIDS related witchcraft assertions as a manifestation of a traditional system that is undergoing change and in the process a vacuum is filled in by feelings of anxiety, uncertainty and spiritual insecurity, in seeking an explanation for the affliction. Ashforth (1998, 2000) argues that:

...the repertoire of available interpretations for misfortunes such as AIDS includes concepts of witchcraft and understandings of invisible agency that are substantially different from those of western biomedicine. This has major cultural and political implications. The extent of stigma, denial and risky behaviour cannot by people aware of the dangers of infection – be understood unless the dimensions of ‘spiritual insecurity’ in everyday life are comprehended.

The question of witchcraft creates a paradox in that some people in society sympathize with the HIV/AIDS afflicted individual and his or her family and yet at the same time they avoid them. As stated earlier on the reason for the avoidance is that they do not want the ‘bad luck’ from that family to ‘rub’ on them as well. As a result this avoidance isolates the entire family from the mainstream society and consequently this avoidance comes out as some form of social stigma because the family now has a negative mark or label attached to it.

You see this disease is blood borne and I always explain that to my patients even though some of them insist that they were bewitched – then I explain to them that if it is about bewitchment then there is little else I can do to help except maybe to write a reference letter to a Sangoma or Faith Healer explaining that I have examined the patient but based on their and allegations I recommend that the healer offer their services because that would be in line with his training and not my training (Views of Masia WCJ 12 CM).

Yet Dayoff expressed himself this way:

I believe most people do believe that HIV/AIDS is transmitted through the blood but a few other people believe that it can be transmitted by witches through casting their spells upon you. I mean nowadays witches are known to cause someone who crosses their path to develop a stroke and they do that by ‘remote control’(casting a spell) – therefore some people argue that witches can send HIV/AIDS to infiltrate your blood by casting a spell upon you. I am not saying I support that argument as I am merely highlighting what other people believe around here and this implies that as it is in our African culture – therefore the services of a Sangoma or traditional healer can be enlisted to try to get rid of this spell. Now as a Black man you know as I do that certain rituals have to be performed including asking for guidance and protection from one’s ancestors against these witches and HIV/AIDS (Views of Dayoff WCJ 08 CM).

Still another participant, Elisabetha expressed her views this way:

Many in White City here simply employ the denial defense mechanism and blame witchcraft for dissipating the health of their loved one – eg, they blame ‘isidliso’ which is known as black poison that is sent by casting the ‘bad medicine’ on

someone's food unknown to him or her. That is why blame is then apportioned to the boyfriend or girlfriend because they are people who are close enough to be near the infected's food aside from his or her family (Views of Elisabetha WCJ 15 CM).

Symptoms such as wasting away, diarrhoea and tuberculosis as exhibited by many HIV/AIDS positive people correspond very well to the traditional knowledge and beliefs centred on someone who has been bewitched. This also ties in very well with the South African literature on HIV/AIDS especially as noted by Ashforth (2004).

Therefore, there is harmony in terms of factual accounts noted during fieldwork and observations cited in the theoretical framework and literature review chapter.

### **4.3 MODE OF HIV/AIDS TRANSMISSION AND SECONDARY STIGMA IN WHITE CITY**

The reasons for stigma vary and they also range from malicious comments elicited by jealousy because the afflicted and his or her affected family enjoy a better social status and success, to issues pertaining to ignorance of the HIV/AIDS disease, entrenched traditional beliefs as well as to simple issues concerning stereotyping and apportioning blame to the 'others'.

#### **Sexual Promiscuity**

Sexual promiscuity is a theme that strongly emerged during interviews with many research participants. The views of the participants are in agreement with the literature review because sexual promiscuity is said to be a social and religious taboo and those who engage in it are viewed with disdain by society. Promiscuity elicits issues of morality and those found wanting are viewed as a threat to social stability because so many vital social institutions, such as marriage and the family, can easily fall apart if this aspect of human sexuality is not sternly regulated.

In the context of this study and in harmony with the theoretical framework and literature review secondary stigma comes as a result of some people in society who view HIV/AIDS as a disease visited upon the sexually promiscuous people and other people of lower morality such as sex workers, homosexuals, drug addicts, the poor and so on. Therefore, when infected

this category of people would further suffer what Goffman (1963) would classify as double or compound stigma.

The following are the views expressed by Dayoff during fieldwork:

In short HIV/AIDS is caused by infidelity – you find that I have several partners and those partners each has several other partners. So as we sleep around and our blood and bodily fluids intermingle we find ourselves acquiring this HIV/AIDS disease. This disease is blood borne and comes about not because of punishment from God or the ancestors but as a result of people's promiscuity as they engage in multiple partner sexual relationships. On the other hand I hear that one can be infected by touching contaminated blood – as to how I do not know but I think maybe if you happen to kiss somebody and you have a sore or cut around your mouth then transmission will happen because if the blood comes into contact with your skin and you happen to have a cut or a wound then that could possibly be an entry point no matter how small the cut or the wound. These people are rotten apples who come from bad families (Views of Dayoff WCJ 08 CM).

Polygamy is the other cultural factor that some participants viewed as immoral behaviour that helps to proliferate HIV/AIDS. One respondent, Mphatlalatsane put it this way:

Africans, especially the men, have to change some of their behaviour steeped in their cultural practices that make them more vulnerable to be manipulated by other nations bent on re-colonizing them. You see this culture of polygamy and men priding themselves for being 'real men' by maintaining multiple sexual partner relationships, has got to come to an end. Whatever the circumstances, a man can never satisfy so many women at the same time – most men find it very difficult to satisfy only one woman now what about satisfying 2, 3, 4, or 7 women or more all at the same time? There is also the issue of jealousy amongst the women which can spark off much disloyalty as one of the wives can perceive the others to be favourites at her expense and thus vengefully engage in extra-marital sexual affairs. The Western governments know that vulnerability of the African man's culture and thus may have developed HIV/AIDS with that in mind knowing full well that not sticking to one partner will help in quickly spreading this HIV/AIDS disease (Views of Mphatlalatsane WCJ 11CM).

The misplaced allegation of promiscuous and irresponsible behaviour coupled with the contamination or pollution of the blood is not only restricted to the infected individual. Close associates like family members, friends, colleagues, spouses, care-givers and the significant others are also suspect of immoral promiscuous behaviour which is defined by society as a taboo. Therefore, they are even more suspect if they choose to be compassionate towards the infected and their perceived collusion results in them being victims of secondary stigma.

I think with HIV/AIDS it is the way people get it..... If you look at the history of the disease I am being reminded of a television documentary I was watching the other day – more especially because it is 'World AIDS Day' today I also remember that initially

people infected by the disease homosexuals, drug addicts sharing needles and people having unprotected sex and so those are people 'different other' in society – I mean people who crossed the line and dabbled into social taboos. It is associated with promiscuous behavior and another negative factor that elicits stigma is that HIV/AIDS arouse fear in people as it is associated with death and therefore people become scared to enter or visit the home of the infected person and as a result the entire family suffers some form of rejection and isolation too (Views of Madile WCJ 03 CM).

Promiscuity is a theme that strongly comes out of the literature review and in particular, Patient and Orr (2003) as cited in Deacon, Stephney and Prosalendis (2005: 26), suggest that a series of shared beliefs underlie much of the stigma against people living with HIV/AIDS (PLHA's) in Southern Africa. These beliefs are often unconscious and contradictory, but help to justify and create discriminatory behaviour against PLHA's. They are as follows:

- (1) 'If you have HIV you're going to die, I won't invest resources in you' (AIDS=death).
- (2) 'HIV/AIDS is a punishment for sin' (AIDS = Sex = Sin).
- (3) 'We cannot change the way we do things' – for example, condoms challenge cultural norms about procreation, and culture and tradition cannot be challenged (AIDS = Condoms = Contraception = Cultural taboo).

## **Pollution**

Pollution is a theme that also emerged during interviews with participants and is without any doubt in agreement with what is noted on that aspect in the literature review and now to further substantiate let us see how Tau ea Matshekha, one of the research participants, explained this concept of pollution:

Pollution is a result of antagonizing God and one's ancestors by sleeping around with a menstruating woman, a widow still in mourning, a woman who has just committed an abortion and a woman who has just had sex with another man. Such women are said to be 'hot' and unclean as their blood is said to be 'dirty' until they undergo certain traditional cleansing rituals then they are dangerous as they will keep on spreading these sexually transmitted infections that include HIV/AIDS, syphilis, herpes and gonorrhoea. I do not want to associate with such people nor anyone from their households for fear of letting their bad luck rub on me (Views of Tau ea Matshekha - WCJ 10 CM).

Firstly, the fact that many Africans still cling to their cultural norms, values and beliefs makes it important for social scientists to understand the African medical perspective of the aetiology of HIV/AIDS. Some 70% to 80% of the general African population still consult traditional healers for their medical, social, emotional and psychological problems. Secondly,

the fact that many African women in sub-Saharan Africa still engage in the cultural belief of vaginal practices makes it even more important to understand the implications of these vaginal practices on the prevention, testing and treatment of HIV/AIDS.

Therefore, as a starting point one has to understand that the African perspective on the aetiology of HIV/AIDS differs from the Western biomedical idea of the 'germ theory' that explains that people get sick because of the germs and viruses that get into their bodies from the outside environment. In the African perspective the transmission and symptomology of HIV/AIDS is centred on their cultural beliefs of pollution, ancestor intervention and sorcery which are deeply rooted beliefs in these societies despite the extensive AIDS awareness and education campaigns in many parts of Southern Africa.

For instance, "a fairly common belief about the origin of AIDS is the concept of pollution, which Green defines as 'a belief that people will become ill as a result of contact with, or contamination by, a substance or essence considered dangerous because it is unclean or impure'." (Green, 1999: 13).

Green (ibid) further states that there are three main sources of pollution as understood by Africans and they are:

...female reproductive fluids, death and contact with strangers.

Amongst the list of pollutants are homicide, birth, death and sexual intercourse with someone in a state of pollution especially if one commits a sexual act with someone still in mourning for a spouse, a relative or an abortion. Pollution is associated with a person being in a twilight state between life and death as a result of being in contact with something that is impure or unclean.

According to (Walker, Reid and Cornell, 2004: 98-99):

In one survey traditional healers attributed AIDS to a failure to obey post-partum or mortuary taboos; "dirt"; or "dirty blood" is a fairly common element in explanations of AIDS and other STD's. If a person's sexual partner has "dirty blood," it is believed that infection can occur.

According to Green (1999:163) "dirt" is identified as a code word for pollution, and states that it carries connotations with moral wrongdoing or the violation of taboos.

Seeing that traditional healers are said to outnumber biomedical doctors, it makes sense to empower traditional healers to be able to perform their duties in conjunction with biomedical professionals, as in any case the ...clinical burden of AIDS in Subsaharan Africa is handled by traditional healers" (Mills, Curtis, Dugald and Izzy (2005a; 465).

Call it a myth or anything but the reality is that many ordinary African people still believe that:

...AIDS may also result from contact with the clothing, urine, or other polluting substances of an infected person (Lidell, Barret and Bydowell, 2005: 693).

Pollution is an act of 'victim blaming' because absolute responsibility is placed on the decisions and actions of an infected person. A man infected with HIV/AIDS may be blamed for having slept with a widow in mourning. Acquiring STD's may also be viewed as punishment for stealing from neighbours, neglecting ones ancestors or for misbehaving. This is an interesting intersection point between traditional medicine and biomedicine in the fact that 'behaviour' is an underlying factor in terms of acquiring HIV/AIDS or other sexually transmitted diseases, whether that behaviour was through sexual contact with another or through neglecting ones ancestors, ignoring social taboos, or any other kind of unsanctioned behaviour.

### **Contamination**

Contamination is also a theme that emerged during interviews with participants and it corroborates the literature reviewed because as previously demonstrated in chapter 2 people who are HIV/AIDS positive as well as their associates are viewed unfavourably by society as people who are daring enough to have crossed the socially set line that bars people from committing taboos. In this instance the religious and cultural values of a society are called into question and whosoever is found to have defiled that moral code is ostracized by society and viewed as a dangerous threat. The African view of personhood is that an individual is part of the whole and in this case the whole is the family and other close associates and therefore if an individual has a spoiled or tarnished identity, then the entire family members constituting the whole also suffer a spoiled identity that negatively defines them as a danger to society by virtue of having one of their own infected by HIV/AIDS.

In a study done in Lesotho by Germond and Molapo (2006: 30) elaborate on the Basotho concept of life (bophelo) and the chain of human relationships and identity this way:

Plants have bophelo, animals have bophelo, and human beings have bophelo, the earth has bophelo. At a more complex level bophelo is full human life in its complex expressions and social relationships. Here bophelo is social. Thus a family can have bophelo. So can a village or a nation. In this sense bophelo refers to the quality of life, the total wellbeing of society in all its elements and relationships. In Sesotho, a village, a person or a family who lacks bophelo, not in the absolute of being dead, but in this social sense, has an impaired existence. Their wellbeing is compromised. They are in a state of dis-ease.

It is three years now that we have been living in this house with my wife's nephew who was rejected by her parents and siblings – who also stay in another section of White City - for fear of being a health risk to them and embarrassing them by acquiring this strange illness without a cure (Views of Tshepe WCJ 07 CM).

Tau ea Matshekha put it this way:

For instance one of my clients who lives in White City was last week insulted by an elderly woman next door neighbour who called her a slut who is HIV/AIDS infected and is a danger to their men and society. She was she was walking back to her home from the nearby shops and as she went past this woman's house she started insulting her from inside her own yard (Views of Tau ea Matshekha WCJ 10 CM).

And yet Tacash expressed his views this way:

Yes there is stigma and I believe it has to be there because how then do you knowingly touch someone that you know can infect you at any time. I mean be reasonable 'Jack' - this is not isolation or punishment but the reality is that this person is infected and then you have to gamble with your life and pretend that they are not infected! Talk about consequences these are the consequences of their unprotected sex – although I have much pity for people who acquire the disease because they are rape victims or unfortunate recipients of contaminated blood you know the story 'Jack' – I mean people who did not carelessly sleep around but accidentally acquired this disease (Views of Tacash WCJ 14 CM).

Therefore, these opinions as expressed by the research participants are in harmony with the theoretical framework on stigma as stated earlier on by the following academics:

The concept of “unclean” and “impure” relate to ancient taboos of danger beliefs that are relevant on a physical level but that also symbolically express the moral values of the of the culture (Madru 2003: 42).

Douglas (1966: 3) goes on to explain further:

At this level the laws of nature are dragged in to sanction the moral code: this kind of disease is caused by adultery, that by incest.

These citations by Madru (2003) and Douglas (1966) further support the fact that HIV/AIDS infected people as well as their close associates are regarded as being a dangerous threat to society and therefore need to be sanctioned. That is why in most cases these infected and affected people are rejected and isolated by society.

### **Imminent danger and the fear of death**

This theme is also in agreement with the literature review as the fear of the unknown makes people to fear death especially if the process of dying is a slow and excruciating process that

sparks off humiliation as a result of gossips and unfriendly attitudes as people see the infected person wasting away and becoming a shadow of the former self. This wasting away as a result of sickness is often the source of secondary stigma that also rubs on the family, friends, fiancée, caregivers, and others closely associated with the infected person.

Let us now look at the views of Mantsopa as expressed in the interview:

It is associated with promiscuous behavior and another negative factor that elicits stigma is that HIV/AIDS arouses fear in people as it is associated with death and therefore people become scared to enter or visit the home of the infected person and as a result the entire family suffers some form of rejection and isolation too (Views of Mantsopa WCJ 03 CM).

The following are the views of Masia:

There is also re-infection in the case whereby one person sleeps with someone else who already is infected and the combination of the two strains of the virus produces a much stronger and deadlier virus that normally speeds up the process to full-blown AIDS and then eventually death (Views of Masia WCJ 12 CM).

Gay men, African immigrants, Blacks, Sex workers and Drug users, who are often referred to as 'most at-risk populations' (MARPs) are blamed and thus stigmatized through a lengthy process of association linking promiscuity, poverty, substance abuse, crime, the fear of the unknown and death among other things. This makes it imperative to note that these people seldom suffer in isolation but their loved ones and close associates are touched by secondary stigma by virtue of their proximity to them.

Data collected from the fieldwork is in line with the literature review and the theoretical framework as qualified by the views of Parker and Aggleton (2003: 16) who explain that:

..... stigma and social inequality are intertwined as they co-exist in the same environment.

Drawing on the concepts of vulnerability and social capital to understand the relationship between health and social inequalities better, Gilbert and Walker (2002:1097) point out the historically marginal position of Black women in the economy and explain that more young African women aged 25 years and more are less educated as compared to their male counterparts.

Poverty and unemployment are a seed bed for disease and other social problems and when paired with secondary stigma and primary stigma can create a very negative social environment bordering on the daily violation of human rights.

Isak Niehaus (2007) on the other hand, in his research done in the rural community of Bushbuckridge, in Mpumalanga province, raises the concern about HIV/AIDS infected people dying a social death before their actual physical death. This comes as a result of stigma which translates into the isolation of the patient by some close family members, friends and the family at large. These close associates of the infected are themselves scared of death as result of the fear of the unknown and therefore tend to avoid contact with one of their own who is in the process of dying a slow death. The preoccupation with death disrupts interpersonal relationships and leaves the infected person without a solid support system for later on when HIV turns into full-blown AIDS. In that full-blown condition, they become vulnerable as their immune systems are very weak registering a CD4 count below 200. They lose physical strength, tire easily, lose weight rapidly, develop acute diarrhea and sometimes lose the use of their legs and thus become immobilized as they have to rely on other people to provide them with their most basic needs like food and water, as well as to clean them up whenever they have soiled themselves. Their unfavourable physical condition subjects their families and close associates to secondary stigma.

#### **4.4 SECONDARY STIGMA IN WHITE CITY**

HIV/AIDS related secondary stigma is the main objective of this study and the fieldwork data collected is in agreement with the literature review about the existence of such a phenomenon. Therefore let us have a look at how HIV/AIDS related secondary stigma manifests itself in White City.

In-depth interviews yielded evidence of the existence of secondary stigma in White City as the following opinions expressed by Tshepe and some other research participants attest:

Normally the primary stigma is reserved for the infected person but other people associated with the infected person such as family, friends and others also get a bitter taste of that stigma as it happened with me and my wife for 'harbouring' her sick nephew. Word soon spread around White City that we were living with so and so who had AIDS and therefore are also a health risk. Many people, including my neighbours

started avoiding us and calling us by offensive names. One day I secretly organized with our ward councilor to coordinate a health education campaign targeting mostly my neighbourhood so that the health promoters could give education and scientific facts about the nature of the disease. This was done at our community centre and people were lured by the offer of free food, soft drinks and the presence of some celebrities who graced the occasion. After that session things started becoming better and some of my neighbours started talking to us again and confessing to having been ignorant about the disease (Views of Tshepe WCJ 07 CM).

And yet Maria, a 56 year old, lay health worker expressed her experience of secondary stigma this way:

Oh yes there is - as you can understand my sister's children are now orphans and the youngest sometimes gets insulted by other children in the playfield at our local school and gets referred to as the 'child from the AIDS' family. Where did these little ones get this information? The 19 year old boy had a short lived affair with a girl two streets away- the girl's parents, especially the mother, asked 'my boy' to stay away from her daughter if he does not want to find himself in serious trouble – I mean she emphasized that her daughter is not about to be given AIDS by someone who might already be infected due to the fact that he lived with AIDS at his home – i.e. that was a reference to the boy's deceased parents (Views of Maria WCJ 09 CM).

The views and opinions of the research participants interviewed seem to be in harmony with the theoretical framework and the literature review as discussed in chapter 2. Seemingly, secondary stigma is universal because in the literature review section, it is mostly the experiences of people suffering secondary stigma in the United States of America, that are explored and yet their experiences bear a very similar resemblance to those of people in White City.

The saddest case of all was expressed by Masia, a medical doctor, who explained the prevalence of HIV/AIDS stigma in White City this way:

Yes there is stigma – for instance when many people bring their patients who are too weak to walk from home to my surgery, they just abandon them in the queues and hastily leave the premises lest they be seen in their company for fear of also being stigmatized by association. However, they normally phone my receptionist assistant to find out if the infected has finished with his or her consultation with the doctor. Completion of the consultation process then means that the escort can come to pick up the patient and quickly whisk them away before many people who may happen to know them can see them (Views of Masia WCJ 12 CM).

In explaining secondary stigma against family members of people living with HIV/AIDS, Borgat et al. (2007: 250) explained earlier in the literature review section that a few children reported losing friends due to their parent's HIV status, usually because friends' parents prohibited the friendship.

Irrational fears of contagion and avoidance of other infected and affected people are a reflection of factual ignorance around the disease. It would seem that the initial feelings of shame, guilt, low self-esteem and self hatred change after receiving information and counseling about HIV/AIDS and its routes of transmission.

Secondary stigma can also be viewed as a reflection of a lack of knowledge, on the part of the perpetrators because in many cases, one realizes that those that perpetuate the stigmatization of the others do not themselves know their own HIV/AIDS sero-status. Now the irony is that with the passage of time when they discover that they are also infected they get a 'shock of their lives' and start being hard on themselves for having looked down upon others in their hour of need. This also shows a vicious cycle of victim blaming taking on the format of self-blaming accompanied by shame and guilt feelings that are not a positive precondition necessary for effecting successful emotional, physical, spiritual and physical therapy. Therefore, intensive counseling programmes are needed to be done by trained professionals to help minimize the psycho-socio negative effects of secondary stigma and other forms of stigma.

#### **4.5 CONSEQUENCES OF STIGMA**

Consequences of stigma are a theme most dreaded by many research participants. This theme is also in agreement with the literature review and revolves mostly around felt or perceived and enacted stigmas. Avoidance, rejection, isolation and so on are examples of felt or perceived stigma which very subjective in nature as it relates mostly to the infected persons, their families and other their associates who usually withdraw from social activities on suspicion that other people are looking down upon them, gossiping about them, accusing them well as treating them badly for showing their compassion and giving care to the infected person. This kind of suspicion may be based on reasonable grounds or it may just be the result of feelings of guilt bordering on paranoia. On the other hand physical violence against the infected individuals or people associated with them is an example of enacted stigma and it is objective in nature. An example at hand is that of Gugu Dlamini who was murdered by some of her community members, in the province of Kwazulu Natal, after publicly disclosing her sero-positive status within the context of World AIDS Day.

##### **Rejection and Isolation**

Rejection and isolation is a theme in agreement with and also highlighted very well in the literature review. This theme was the first to emerge very strongly during interviews with

participants. These two phenomena can manifest themselves in various ways that can either be emotional, psychological and physical.

The data coming out of the fieldwork shows that rejection and isolation are a phenomenon directed not only at HIV/AIDS infected people but also at their families, friends and other close associates especially if they consistently embrace and show compassion towards the individual infected. This is secondary stigma as it extends well beyond the boundaries of an individual and spills over affecting the family, friends and other people closely associated with the infected person. The African view of personhood and life is motivated by the existential philosophy of '*Ubuntu*' in isiZulu and '*Botho*' in Sesotho and it views personhood as an interlinkage of personal networks starting with the immediate family members, reaching out to extended family members, friends, neighbours, colleagues, close associates, deceased ancestors, God, plants, animals and the entire natural cosmic world. A good life means good health, which means '*Bophelo*' in Sesotho and the Sesotho concept of *Bophelo* implies harmony – the biological harmony experienced by one's good functioning physical body, social harmony in terms of good relationships with one's family, friends, neighbours, other close associates, the environment as well as the abundant material fortunes that God, the ancestors and life bestow on a person. This harmony is said to emanate from within the family (home) or '*Lelapa*' in Sesotho and a good *Lelapa* generates healthy and functional members valued by society. Therefore, in the African culture *Lelapa* (Family) plays a pivotal role in the analysis of an individual and determines how other members of society treat the individual. Therefore good or bad residue emanating from behavioural conduct and other matters affecting the individual affect every member of that family. Nevertheless, it must be indicated that all the 15 research respondents interviewed, agreed that they also felt rejected and isolated as a result of associating or living with someone who is infected by HIV/AIDS. The following are some of their views, as expressed by two participants, Sporo and Sekhothu:

My brother, let me tell you – people can be very cruel because not only do they avoid and isolate the infected person but they also avoid and try to isolate other people closely associated with the infected – eg. Family members, employed domestic helpers, boyfriend, girlfriend and so on. I recently lost a brother who succumbed to HIV/AIDS. He was very popular amongst his male friends and beautiful women were always chasing after him probably because he had a very friendly personality and the fact that he was well dressed as he worked as a chauffeur for a very rich White businessman and therefore earned a decent salary and could afford a better lifestyle. He often funded weekend parties with friends but let me tell you he died a very broken man, being betrayed and isolated by all the friends he used to have a nice time with, some never even came to his funeral. (Views of Sporo WCJ 01 CM)

Sporo's views are also backed up by the views of Sekhothu who stated that:

Yes there is a lot of stigma around here – for instance some members of the family, like in the case of one of my infected congregation members whose sister used a wet towel to beat him up whenever he had soiled himself. Although he now had full blown AIDS, very weak and had lost control of most of his bodily functions, he was constantly reminded by the sister that: 'this is the result of fucking around' – in a literal and figurative sense. The sister reminded the poor brother that when he was employed he never sent money home for their upkeep but deserted them and went to live in a flat in Hillbrow and only comes back now that he is sick. The sister would add now: now we are the laughing stock of neighbours and everybody! Nobody ever wants to neither associate with us nor pay us a visit again and it is all because of you. Where are the 'magoshas' (prostitutes) of Hillbrow you fucked around with (Views of Sekhothu WCJ 06CM)?

It would seem that the concept of individualism and individual responsibility is a Western concept and thus foreign to Africa. There is a Zulu proverb that says '*Umuntu Ngumuntu Ngabantu*' which translated into the Sesotho languages means '*Motho ke Motho ka Batho*' and equals the English idioms 'You are because I am' and 'No Man is an Island'.

Therefore, emanating from the interviews are many shades and levels of rejection and isolation and one of those is xenophobia which a phenomenon that thrives on 'othering' or 'blaming' foreigners for the ills experienced by a community or nation.

### **Xenophobia**

Mphatlalatsane who is a Mozambican citizen but lives and works in South Africa expressed the fact that as foreigners they are doubly stigmatised, given awful and derogatory names such as 'makwerekwere' and viewed as carriers of disease including HIV/AIDS. He put across his opinion this way:

I am renting a backyard room in White City Jabavu and I was also treated badly by my neighbours for taking care of my Mozambican friend who was very sick due to his weakened immune system as a result of being infected by HIV/AIDS. I housed him temporarily at my place to take care of him because his landlord had thrown him out of the backyard room he rented into the street. This is what the landlord said on realising that my friend was sick: 'I do not want to have a 'makwerekwere' dying in my yard, I do not want to have trouble with the authorities and my neighbours for keeping a risk of an HIV/AIDS dying 'makwerekwere' let alone contracting HIV/AIDS myself by sharing the same living space with such a sick foreigner (Views of Mphatlalatsane WCJ 11 CM).

Xenophobia is another shade of the rejection and isolation phenomenon that concurs with evidence in the theoretical framework and the literature review as the following comments by researchers validate the existence of this phenomenon relative to the discrimination, blaming and ill-treatment of foreigners. Parker and Aggleton (2003: 16) observe that:

Ultimately, therefore, stigma is linked to the workings of social inequality and to properly understand issues of stigmatization and discrimination, whether in relation to HIV and AIDS or any other issue, requires us to think more broadly about how some individuals and groups come to be socially excluded, and about the forces that create and reinforce exclusion in different settings).

Furthermore, Herek [2002] in Deacon [2005: 15] contextualizes Goffman's definition of stigma by attributing a social perspective whereby an individual infected and affected by HIV is viewed with suspicion and is therefore negatively valued by society.

However, other researchers cite exclusion as a function of the political economy present in the world today that perpetuates social inequalities in order to maintain the status-quo tipped in favour of the powerful social groups. Gay men, African immigrants, Blacks, sex workers and drug users are blamed and thus stigmatized through a dual association of promiscuity and poverty.

### **Linguistic Euphemisms**

The theme of linguistic euphemisms emerged during interviews and seems to corroborate what is written in the literature review about the use of derogatory language to refer to HIV/AIDS infected and affected people. The data collected from interviews shows that people have developed codes when gossiping about someone who is infected or they suspect to be infected, due to a dramatic loss of bodily weight or sheer wasting away and therefore they sometimes carelessly make use of these codes in the presence of someone who is infected or affected and happens to know about these codes. A study conducted by the International Centre for Research on Women (ICRW, 2003: 38) stipulates that:

Language and its negative power is one of the primary vehicles through which stigmatization occurs. A community leader in Zambia explained that, "... it is not sometimes the disease that kills these patients, it is the bad words and remarks from people. Gossip has harsher consequences for women who generally rely more heavily than men on social networks, particularly when their access to and control of economic resources is limited, as in our study.

Now this is bad practice and constitutes both emotional and psychological trauma bordering on abuse of the victim. Analyzing the expression ‘social networks’ is implicit of family, friends and other close associates and also highlights the fact that these networks are negatively affected by the negative attitudes and gossips that result in them experiencing secondary stigma. Some of the stigmatizing linguistic codes referring to the infected people are cited below as expressed by the research participants:

- *O na le ‘magama’* (Sesotho) – means he/she is carrying the three letter words HIV/AIDS (Views of Sporo WCJ 01 CM).
- *O palame Z3* (Sesotho) - means he /she is riding on a BMW Z3 in reference to the three letters comprising HIV (Views of Malile WCJ 03 CM).
- *O dula le Hlengiwe Ivy Vilakazi* (Sesotho) – means he/she lives with a loving or sexual partner called Hlengiwe Ivy Vilakazi which is a coded reference to HIV/AIDS (Views of Tshepe WCJ 07 CM).
- *U na mabandi* or *O na le mabanta* (Zulu and Sesotho) – mabandi and mabanta means belts in English and is used as a reference to the shingles appearing on the skin of the infected person (Views of Masia WCJ 12 CM).
- *U shawe hi* ‘lightning’ (Zulu) - meaning that she/he has been struck by lightning in reference to the swiftness and fatal nature of the lightning hazard (Views of Tacash WCJ 14 CM).
- *Inculaza* is a Zulu word for HIV/AIDS (Views of Elisabetha WCJ 15 CM).

Language and its related euphemisms such as those stated above is therefore recognized in the methodological framework and literature review as a social structure used by other people, not infected and affected by diseases such as HIV/AIDS, to discriminate against those infected or affected. Alonzo and Reynolds (1995) provide a more complex reading of Goffman, by suggesting that stigma represents a language of relationships and does not only centre around one attribute such as a physical or mental deformity.

The stigmatization and discrimination against other infected people and their families are an effort to reaffirm normalcy by those not infected and affected by HIV/AIDS. Therefore, it would seem that the presence of primary stigma is often accompanied by secondary stigma directed at those associated with the infected person.

## **Gender Disparity**

Gender disparity also emerged strongly as a theme during the in-depth interviews. This aspect corroborates the literature review on this phenomenon which explains that women seem to be more vulnerable to the HI virus because of their biological anatomy and the fact that they also possess lesser economic power as compared to their men folk and therefore have little negotiation power in terms of enforcing condom usage in a sexual encounter.

Facets of gender insensitivity bordering on sexism and discrimination have been noted during fieldwork because it would seem that stigma is experienced very acutely by poor young Black women who are often victims of emotional, psychological and physical abuse. Elisabetha, a 47 year old research participant, endured secondary stigma from her neighbours and explained her experiences this way:

Even though I am not personally infected I am the chairperson of an HIV/AIDS support group and often use my house as a meeting place – and considering our openness about the subject – some of my neighbours, especially the men, would pass unfriendly remarks on seeing some of these infected ladies coming into my house for one of our meetings. They would pretend to be calling aloud to their teenage sons saying ‘Siyabonga, Siyabonga, where are you my son? It is ‘World AIDS Day’ today and be careful not to step into that yard because ‘U Hlengiwe kunye no Ivy Vilakazi (HIV/AIDS) are having a meeting today and discussing how to better infect us all – these women are immoral and have an unquenchable sexual appetite -Sis.....Phew’ (Views of Elisabetha WCJ 15 CM)!

This kind of abusive behaviour against these poor and vulnerable women is not only restricted to the emotional and psychological level but can actually transcend those boundaries as it becomes more intense and physical as described by Mamokete:

One lady from the other part of White City was literally physically beaten by her elder brother for having brought shame to the family who now had to endure the gossips and cruel comments directed at other members of the family by neighbours and other people. Apparently the brother accused women of being bitches who go about spreading HIV/AIDS because they cannot control their lust for sex. She decided not to lay assault charges for fear of antagonizing other family members by getting his brother arrested and thereby exacerbating her already hostile home environment and risk further rejection and isolation (Views of Mamokete WCJ 05 CM).

All the above cited cases on secondary stigma do qualify and concur with the literature review on this despicable phenomenon and now let us have a look at what the literature has to say about this phenomena:

The individual who is related through the social structure to a stigmatized individual – a relationship that leads the wider society to treat both individuals in some respects as one. In general, the tendency for a stigma to spread from the stigmatized individual to his close connections provides a reason why such relations tend to be avoided or to be terminated. (Goffman 1963: 30)

In further explaining secondary stigma against family members of people living with HIV/AIDS, Borgat et al. (2007) explains that, in a study carried out in America, a few children lost friends because of disclosing their parents' HIV/AIDS status.

Therefore, discrimination related to HIV/AIDS stigma is another worrying aspect that serves to hamper progress in the fight against this epidemic.

'The National Strategic Plan of South Africa 2007 – 2011' highlights the differences in the accessibility, strength and concentration of HIV/AIDS prevention programmes. For example, despite the fact that many people have the knowledge about HIV prevention, the daily infection rate is still way too far considering programmatic efforts by the authorities and other stake-holders in trying to curb the overall HIV/AIDS incidence and HIV/AIDS prevalence levels. As compared to their men-folk, vulnerability to HIV infection is also considerably higher among women, even though both men and women are targeted for prevention programmes.

UNAIDS (2008) maintains that:

... although a large majority of countries have begun to recognize gender issues in their HIV planning processes, a substantial number of countries lacked budget and policy support for such issues. For example, only 52 % of countries are reported to have a budget dedicated to HIV programmes that aim to exclusively address challenges that women face as far as the epidemic is concerned. This is in spite of there being more than 80% of countries that report to focus on women as part of their HIV reduction strategy. Asia (69%) and sub-Saharan Africa (68%) are reported to be the two regions that have the largest budget aimed at addressing such efforts (UNAIDS 2008).

Discrimination related to HIV/AIDS stigma is another worrying aspect that serves to hamper progress in the fight against this epidemic.

Finally, after the lengthy discussions engaged in throughout this study, it is convincingly apparent that secondary stigma comes as a result of being associated with the infected person

or people. However good or bad the fate of an individual, it is always linked to the family first and thereafter to any other close associates such as compassionate neighbours, friends, colleagues, fiancée and so on. What is also most interesting but disturbing out of this discussion is the element of gender insensitivity propelled by the traditional concept of power relations between the males and females whereby the woman is always considered to be inferior to the man and also blamed for being sexually 'out of control'. As a result women suffer multiple stigmas – first, as women, secondly for being of black pigmentation, thirdly for being poor and finally as carriers of disease.

#### **4.6 CONCLUSION**

Data collected from fieldwork mostly agrees with what has already been written about in the literature review. However, what is notable is the fact that the data collected leaves no doubt that to this day White City, Jabavu is still a stigmatized and traumatized community. This is a poverty stricken environment with high unemployment rates that create conditions for criminal anti-social and other deviant behaviours, especially amongst the youth. The stigma that entangles these youths, especially the HIV/AIDS infected ones, surely rubs onto their family members, friends and other close associates who suffer secondary stigma. In view of the above discussions it is also apparent that the reality of being ridiculed, labeled, blamed, rejected and isolated by other members of the community one's close relationship with the infected person is a nightmare of an experience. Many people accuse these close associates of collaboration in nurturing and hiding the immorality that culminated in the HIV/AIDS infection of their son, daughter and friend. It would further be argued that this is an attitude based on suspicion and not based on fact and therefore seems to be tantamount to the English idiomatic expressions: 'birds of the same further flock together' or the one saying 'show me his friends and I will tell you what kind of man he is.'

Now let us have a look at the coping strategies of some of these affected and stigmatized individuals in a highly stressful and hostile environment of White City, Jabavu.

## **CHAPTER 5**

### **COPING WITH STIGMA IN WHITE CITY**

## **5.1 INTRODUCTION**

In this section of the research report, most themes are also not new and actually agree with the evidence in the literature review, as discussed in chapter 2. However, as already mentioned where there is a lack of evidence from the literature review of this study, further nuances, will be enriched by summoning or referring to evidence from sister disciplines such as anthropology, psychology and from the broader literature on HIV/AIDS. For instance 'rationalization' is a psychological concept for coping with stressful situations but it is still a relevant concept within the sociology and anthropology disciplines as the subject phenomena of these two disciplines is also human existence and its related activities.

It is important to note that all coping strategies are enacted as a survival mechanism in a hostile environment. Coping strategies also relate to the psychological state of the individual, that of their stigmatized family and that of the stigmatized significant others. The adoption of a particular coping strategy is also contingent upon whether the stigma is felt/perceived or enacted. Nevertheless, the following are the expressed coping strategies adopted by the interviewed individuals, their families and close associates in the face of a hostile and stigmatizing environment in White City, Jabavu.

### **Religion**

Religion as a coping strategy is a theme consistent with the literature review and other literature on HIV/AIDS coping mechanisms. HIV/AIDS is a very strange and unique disease in that it baffles western medicine and other alternative medical practices such as African traditional medicine (Sangomas) and so on. Therefore anything that seems to be beyond the healing powers of mankind leaves many people with no alternative but to turn to God to effect a miraculous cure because most religions in the world teach that God the creator is almighty and can turn any unfavourable situation around to favour those that acknowledge and believe in him. In short religion also teaches people that healing also comes from God. The following views of some of the research participants attest to this religious doctrine:

Well, strategies differ from family to family - some decide to relocate to another area or province, others choose to learn more about the HIV/AIDS disease and yet one particular family that I know in White City resorted to religion and became born again Christians with a popular charismatic church based in Soweto (Views of Lehlohonolo WCJ 02 CM).

Another participant, Dayoff, expressed his views in this manner:

Some resort to God and religion and hope for a miraculous cure – especially as they hear messages from some charismatic priests and churches who claim that through faith and the ‘laying of hands’ by their charismatic Pastor then a cure will be miraculously effected (Views of Dayoff WCJ 08 CM).

Gravitating towards religion seems to improve the stress tolerance levels of the infected and affected individuals. Religion seems to offer them an avenue through which they can come to terms with their situation by accepting that the loving Almighty God will intervene on their behalf and bring both physical and spiritual salvation to their situation by effecting a miraculous cure. As Ashforth (1998, 2000) explains, religion must be contextualised to suit particular situations and audiences, such as Africans in Africa. The contextual theology of healing as practiced by the Lord Jesus Christ when he healed lepers, paraplegics, the insane and many other sick people becomes relevant and valued as a demonstration of God’s power. Religion must be made to be less abstract and more sensible because even the Lord Jesus himself preached and healed to his Jewish audiences using parables and metaphors, such as the grapevine, fig tree and many others commonly found within their contemporary Middle Eastern environment.

## **Denialism**

Denialism is also a coping mechanism that is traceable to the literature review and the denialist attitude of the South African government under the leadership of former President Thabo Mbeki and his Minister of Health Dr Manto Tshabalala-Msimang is said to be the cause of many people refusing to go for voluntary counseling and testing. Mbeki’s questioning of the link between HIV and AIDS gave many people a false sense of comfort as they mistakenly understood his questioning to be a denial of the existence of the disease. The cherry on top was added by Minister Manto when she recommended the regular consumption of garlic, beetroot, lemon, ginger and african potato to help boost the immune systems of the infected individuals. Some people including traditional healers capitalized on this statement to encourage the infected people and their families to solicit the services of alternative medicine such as consulting Sangoma’s and various other traditional healers.

Another research participant, Mantsopa, expressed herself this way:

However, many other people infected with HIV/AIDS including their caregivers at home tend to hide the fact that they are infected and I believe it is up to them to disclose and help demystify this disease. When someone is sick, they would opt to say that he or she is suffering from pneumonia, tuberculosis or some lung disease – but they would never say that so and so is suffering from HIV/AIDS (Views of Mantsopa WCJ 03 CM).

Pontsho put it this way:

I think there is an element of denial especially after the controversy created by the former President Thabo Mbeki when he questioned the relationship between HIV and AIDS. The former Minister of Health Manto Tshabalala-Msimang further created a false hope that the daily intake of beetroot, garlic, lemon, ginger and african potato will help cure HIV/AIDS. The views and opinions of influential government figures such as Mbeki and Tshabalala-Msimang created a false sense of security and cast some doubt on the existence of HIV/AIDS – further undermining ‘safe sex’ messages spread by healthcare workers and the media. Many people, especially the gullible youth, neglected to go for testing to check on their HIV/AIDS status. Some even dared to say AIDS is an acronym for ‘American Invention to Discourage Sex’ (Views of Pontsho WCJ 04 CM).

Maria had this to say:

Many families simply deny that their loved one was killed by HIV/AIDS. They would rather name other more socially acceptable diseases such as cancer, tuberculosis, pneumonia, meningitis and many others as the cause of their loved one’s death. You see my family decided to publicly disclose the real cause of my sister’s death in order to avoid gossips aroused by uncertainties and the general human element of curiosity (Views of Maria WCJ 09 CM).

Masia put across his views in this manner:

Manipulation tactics are at play here and obviously many families will deny that one of their own is HIV/AIDS infected and blame witchcraft for their misfortune knowing very well that the mere mention of witchcraft will win them a significant number of sympathies (Views of Masia WCJ 12 CM).

Thus, it would seem that President Thabo Mbeki’s denialism of the link between HIV and AIDS encouraged many people to also deny the existence of the disease under the pretext that it is the White man’s fabrication to control African peoples’ sexuality and sexual behavior which they already ridicule as being promiscuous.

Denialism on the part of the South African government was a bad public relations manoeuvre which had a very negative national as well as international fallout for the government as the following statement attests to that:

Social stigma associated with HIV/AIDS, tacitly perpetuated by the Government's reluctance to bring the crisis into the open and face it head on, prevents many from speaking about the causes of illness and deaths of loved ones and leads doctors to record uncontroversial diagnoses on death certificates (South African AIDS Statistics 2008: 4).

This statement shows beyond any doubt that the government's indecisive response to the treatment of HIV/AIDS is one of the public discourses that encouraged the stigmatization of the disease, the infected and affected people. Hence, denialism by the South African government resonated with the denialist coping strategies adopted by infected individuals and their affected loved ones who saw it as an easier option that comforted them in their pain brought about by HIV/AIDS.

### **Disclosure**

Disclosure as a coping strategy is generously recorded in the literature about HIV/AIDS. Disclosing one's HIV/AIDS status is an act of courage often encouraged by the medical personnel and yet one can sometimes pay dearly as was shown with the case of Gugu Dlamini who was stoned to death for having publicly declared her sero-positive status in the context of a World AIDS Day meeting and was killed by a mob a few days later for 'bringing disgrace to the community' (Associated Press 1998).

Nevertheless, some participants dismiss Gugu's case as one of those unfortunate incidents bound to happen in life and state that they would rather choose the disclosure option because it will disempower the gossip mongers and encourage their families, friends and other close associates to be more sympathetic and supportive towards them.

Now let us see what some participants personally had to say about disclosure and the first one to express his views is Sporo who put across his views this way:

My brother I would definitely not commit suicide but I would confide in trusted members of my family and elicit their support. I would go for regular check-ups and stick to a strict exercise and healthy food schedule (Views of Sporo WCJ 01 CM).

On the other hand Mamokete had this to say:

I do not know but I think I can publicly disclose my status and use that as an opportunity to educate the public about the disease – a demystification campaign of HIV/AIDS seriously needs to be planned, coordinated, implemented and orchestrated by all stakeholders in society and not just be dismissed as the responsibility of the government (Views of Mamokete WCJ 05 CM).

Sekhothu put across his feelings this way:

I would publicly disclose my HIV/AIDS positive status to my congregation and all interested people and I would then use my experience as an example to motivate other infected people to disclose their status' as well so that the public, sooner than later, gets to accept the fact that infected people are still complete human beings with rights, feelings, wishes and desires (Views of Sekhothu WCJ 06 CM).

Dayoff stated his opinion this way:

Firstly, I would not commit suicide but I would try to accept my illness, disclose to my family, friends and close associates because I believe that if you personally initiate disclosure as well as offer them education on the disease – you stand a better chance of not being rejected (Views of Dayoff WCJ 08 CM).

Elisabetha expressed herself this way:

Like I have already stated I have gone public with my positive status and I am receiving antiretroviral treatment (ARV's), exercising regularly, drinking lots of water as well as eating healthy diets with a lot of green vegetables, fruit, white meat and so on and so forth (Views of Elisabetha WCJ 15 CM).

The disclosure phenomenon is extensively cited in the theoretical framework and literature review on HIV/AIDS and its associated primary and secondary stigma. This theme emerged strongly from every in-depth interview conducted with the individual participants and it is a good coping strategy that needs to be encouraged and has the potential to help minimize or eradicate social stigma when coupled with the right timing and the right education by the right people.

### **Non-disclosure**

Non-disclosure is a theme that also agrees with what is recorded in the literature review. Non-disclosure is a form of denialism and a common coping strategy used by many people living with HIV/AIDS. In the literature review section Niehaus (2007) refers to the fear of rejection and isolation as paramount in non-disclosure. However, data from the fieldwork reveals that only one participant declared that he would not encourage anybody, herself included to publicly disclose their HIV/AIDS status.

The following are the views of Tatibi:

I would stick to antiretroviral treatment but I would never disclose that I am sick lest I also become a victim of abuse by my neighbours and other cruel people (Views of Tatibi WCJ 13 CM).

However, other than Niehaus (2007), academics and other authors confirm that this kind of behavior is not unusual as illustrated by the citations below:

People diagnosed with HIV often make the decision to maintain secrecy through strategies of non-disclosure, including hiding their medicines, fabricating reasons for medical appointments, and not insisting on the use of condoms, a behavior that would include vulnerability of disclosure through the initiation of potentially incriminating questions by partners (Madru 2003: 41).

On the other hand Deacon et al. (2005: 4) has this to say:

Although research on HIV/AIDS stigma has been done in the recent past in South Africa, it is important to understand HIV/AIDS stigma in relation to the broader social, political, economic and cultural context, and to address stigma as one of a number of causes of discrimination, reluctance to test, therapeutic non-compliance, and so on.

It would seem that the stigma associated with HIV, makes it very complicated and difficult for both men and women to initiate safer sex because as doing so could have the implication that one's partner is "unclean."

It would also seem that the more the sickness is not visible the more the afflicted individual would try to act as normal as possible for fear of being stigmatized and thus rejected and isolated should it be known that they are infected with HIV/AIDS. Thus the hidden nature of HIV/AIDS also makes it easy for families to be complicit and hide the true nature of the sickness of one of their own for fear of suffering the social fallout by way of being rejected and isolated.

### **Culture and Traditional Beliefs**

Culture and Traditional beliefs is a coping strategy perfectly in agreement with what is recorded in the literature review because, firstly, the fact that many Africans still cling to their cultural norms, values and beliefs makes it important for social scientists to understand the African medical perspective of the aetiology of HIV/AIDS. Some 70% to 80% of the general African population still consult traditional healers for their medical, social, emotional and psychological problems. Secondly, the fact that many African women in sub-Saharan Africa still engage in vaginal practices as part of their culture makes it even more important to understand the implications of these vaginal practices on the prevention, testing and treatment of HIV/AIDS.

Therefore, as a starting point one has to understand that the African perspective on the aetiology of HIV/AIDS resonates with the social model of health and thus differs from the Western biomedical model of health with its 'germ theory' that explains that people get sick because of the germs and viruses that get into their bodies from the outside environment. In the African perspective the transmission and symptomology of HIV/AIDS is centred on their cultural beliefs of pollution, ancestor intervention and sorcery which are deeply rooted beliefs in these societies despite the extensive AIDS awareness and education campaigns in many parts of South Africa.

As Mantsopa, one of the research participants succinctly puts it:

Even though many families turn to God for guidance, solace and hope for a miraculous healing- however, other families consult traditional healers who give them herbal concoctions to drink in order to cleanse their bodies. The intervention of the family ancestors is sought in order to bring about a cure, all family members undergo certain cleansing rituals whereby various herbs are consumed as well as mixed with bathing water to help cleanse their auras ( aura = means seriti in Sesotho languages and in Nguni languages it is called iSithunzi). Special herbs are also administered to cleanse the entire household – i.e. inside and outside the house (Views of Mantsopa WCJ 03 CM).

For instance, in the anthropology literature (Green, 1999: 13) states that:

...a fairly common belief about the origin of AIDS is the concept of pollution, which Green defines as 'a belief that people will become ill as a result of contact with, or contamination by, a substance or essence considered dangerous because it is unclean or impure'.

Green states that there are three main sources of pollution as understood by Africans and they are:

- (1) Female reproductive fluids,
- (2) Death
- (3) Contact with strangers.

Amongst the list of pollutants are homicide, birth, death and sexual intercourse with someone in a state of pollution especially if one commits a sexual act with someone still in mourning for a spouse, a relative or an abortion. Pollution is associated with a person being in a twilight state between life and death as a result of being in contact with something that is impure or unclean.

According to (Walker, Reid and Cornell, 2004: 98-99):

In one survey traditional healers attributed AIDS to a failure to obey post-partum or mortuary taboos; “dirt”; or “dirty blood” is a fairly common element in explanations of AIDS and other STD’s. If a person’s sexual partner has “dirty blood,” it is believed that infection can occur.

Green (1999:163) further states that:

... “dirt” is identified as a code word for pollution, and states that it carries connotations with moral wrongdoing or the violation of taboos.

Seeing that traditional healers are said to outnumber biomedical doctors, it makes sense to empower traditional healers to be able to perform their duties in conjunction with biomedical professionals, as in any case the following authors - Mills, Curtis, Dugald and Izzy (2005a: 465) explain that the:

...clinical burden of AIDS in Sub-Saharan Africa is handled by traditional healers.

Call them myths or anything but as Lidell, Barret and Bydawell (2005: 693) explain, the reality is that many ordinary African people still believe that:

...AIDS may also result from contact with the clothing, urine, or other polluting substances of an infected person.

Pollution is an act of ‘victim blaming’ because absolute responsibility is placed on the decisions and actions of an infected person. A man infected with HIV/AIDS may be blamed for having slept with a widow in mourning. Acquiring STD’s may also be viewed as punishment for stealing from neighbours, neglecting one’s ancestors or for misbehaving. This theme on culture and traditional beliefs is an interesting point of confluence between traditional medicine and biomedicine considering that both view ‘behaviour’ is an underlying factor in terms of acquiring HIV/AIDS and other sexually transmitted diseases irrespective of whether that behaviour was through sexual contact with another or through neglecting ones ancestors, ignoring social taboos, or any other kind of unsanctioned behaviour.

In Africa, any illness which is extraordinary like HIV/AIDS is often explained in supernatural terms.

As Liddel et al. (2005: 693-694) elaborate:

Illnesses which are difficult to cure, which occur abruptly, or are surrounded by an unusual series of coincidences may be interpreted as personalistic, that is, caused by a living person or by the ancestors. Moreover, premature or inopportune death is often seen as personalistic and AIDS is an untimely illness which leads to premature death; it is therefore seen as “unnatural” and can be interpreted as witchcraft.

In terms of disease symptoms there are commonalities and differences between traditional medicine and biomedicine but as Green (1994: 506) found out in a workshop he had with traditional healers in 1993 that:

...the healers differed with biomedicine and cited as symptoms ‘loneliness, self-pity, and the need to have the skin massaged’, as well as having a ‘great appetite’.

On the other hand commonalities in terms of HIV/AIDS symptomology between biomedicine and traditional medicine were identified in 1993 by traditional healers in Green’s (1995: 506) workshop as:

...three biomedically “fully correct” symptoms, such as weight loss, sores, and diarrhoea.

Furthermore, as briefly pointed out earlier, the aetiology of HIV/AIDS is seen by many African traditionalists as an interference by supernatural forces or as an act of witchcraft. In support of this previous statement, Liddell et al.(2005: 694) also point out that:

... to many Africans, epidemics such as HIV/AIDS are most commonly inflicted on a nation or tribe by their collective ancestors” due to a failure to follow traditional strictures.

Health is not an individual issue but is relational and good health is brought about by respecting societal rules so as to bring harmony with one’s family ancestors as well as the collective tribal ancestors. This means that an individual is part of the bigger cosmology and hence the Zulu saying, “*Umuntu ngumuntu ngabantu,*” roughly translated into English as meaning “a person is a person through other people and hence no man is an island.” Good luck or misfortune is said to be brought about by ancestors but if one happens to experience a lot of good luck, then one has to give the ancestors symbolic food like sacrificing a sheep, a goat, a cow, a chicken or any other approved creature as thanks giving for their protection against bad spirits and for giving good guidance over his or her life. Thus, generally speaking, a person has to respect sex to invoke good luck from the ancestors and this can be

done by not sleeping with a menstruating woman, a woman who has just committed abortion or having sex with an uncleansed widow.

The relationship with ancestors is very personal and individualistic in such a way that even a newly born child has to be introduced to the ancestors who will guide in giving a right name for the child. The practice of paying '*ilobola*' is a cultural way of introducing a prospective bride to the grooms family and ancestors. Marrying without introducing the new bride to the ancestors the cultural way implies that the groom's ancestors do not know that new bride and hence she is not protected by them. If she happens to die without having appeased the ancestors by being introduced in a culturally correct way to them, then that means her soul/spirit will perpetually be in limbo until a correct traditional ritual is enacted to appease the ancestors who will then accept the roaming soul into their ancestral court. Ancestral issues are deep rooted in African culture as angry ancestors are said to inflict one with disease including HIV/AIDS. People not buried properly like those who died in war or were buried unknowingly as paupers turn out to be troublesome spirits without peace and can bring bad luck to a relative until a traditional healer identifies the source of the problem and advises that a particular ritual be enacted by the sick individual and his or her family to appease the angry and troublesome spirit. In African sexuality everything is interrelated and forms a picture of a circle. Everything is interconnected and relational to health, the environment, the cosmos, connected to ancestors, connected to life and death, and so on. Having many children is viewed as part of social security in old age and a wider social network.

### **Rationalisation**

This is in agreement with the literature review because in an effort to remain strong in the face of the HIV/AIDS calamity many individuals and families receive comfort and the strength to cope with the difficulties brought by the disease upon them by simply reminding themselves that theirs is not the first nor the last family to be affected by the disease. The following is a comment made by Pontsho:

Other families become philosophical and use 'rationalisation' as a coping strategy and argue that if other ordinary families can fall victim to this disease then they are also bound to have their fair share because after all whether one dies because of HIV/AIDS or any other disease it makes no difference as death is death and everything will come to pass (Views of Pontsho WCJ 04 CM).

Rationalization is another form of acceptance and it seems to provide affected individuals and families with a cathartic effect because acceptance of their predicament makes them feel better about themselves and their infected relative. Feeling better makes them in turn to offer their best humane treatment to the afflicted that also in turn harbours minimal feelings of guilt and shame.

### **Lifestyle Change**

Lifestyle change is a theme that emerged during interviews and is in harmony with the literature review as lifestyle change is a universal phenomenon encouraged by the health authorities and other concerned stakeholders. It is mentioned and encouraged as an important part of therapy in the literature review. Yes, it is true that if people plan their meals carefully and consider what they eat, coupled with regular physical exercise, then they usually lead normal, healthy and long lives. This phenomenon is important as a coping mechanism to help sustain the lifespan of the infected person. Some known infected celebrities in America and in South Africa are known to be living with HIV/AIDS for over 20 years and attribute that to a strict balanced and healthy diet regimen accompanied by regular physical exercise. On the other hand a change in lifestyle is bound to affect family resources, influence what they eat as well as how their meals are structured and prepared.

I would be deeply hurt – I don't know what I would do but I think I would have to adopt a healthier and more cautious lifestyle (Views of Mantsopa WCJ 03 CM).

Another research participant expressed their views this way:

I would eat healthily, drink a lot of water, exercise regularly and take on my antiretroviral treatment as prescribed by the doctor. I would try as much as possible to lead a normal lifestyle because I have seen how people who look well after themselves can prolong their lives by decades – look at the cases of so and so..... who are celebrities in South Africa, are HIV/AIDS positive for the past 25 years but they still look good and strong (Views of Mamokete WCJ 05 CM).

The literature review section points to the fact that, the former Minister of Health, Dr Tshabalala-Msimang regularly encouraged the infected people to eat healthily and to include in their daily meals garlic, beetroot, lemon and ginger as substitutes for the expensive antiretroviral drugs desperately needed to boost the compromised immune systems of poorer people.

Well for me it is an easy choice as I will have to live on planned healthy diets, exercise regularly at my local gym in Midrand, drink a lot of water and practice safer

sex with a condom – but above all I will make a public disclosure because it would be hypocritical of me to say the government or so and so must do this or that to demystify HIV/AIDS and yet me as a doctor fail to see myself and my positive status as an opportunity to teach others about the disease and thus contributing to its demystification (Views of WCJ Masia 12 CM).

This positive outlook helps people counter the effects of stigma and looking good also helps to bolster one's self esteem which is a vital ingredient in maintaining a healthy and balanced emotional, psychological, spiritual and physical state.

### **Fatalism and suicidal tendencies**

This theme is unconfirmed in the literature review cited but apparently, according to some participants interviewed, some individuals get very distressed upon about their learning HIV/AIDS positive status and decide to commit suicide. Suicide in itself is inclined to be viewed by many people as an act of 'escapism' whereby the infected individual cannot bear to stand the emotional, physical, social and psychological effects of being rejected and isolated for being HIV/AIDS positive. The fear of stigmatization plays a key role in influencing some individuals to terminate their lives.

As soon as I know I would swallow poison or shoot myself depending on my mood you know but definitely I would not wait to be ridiculed by people and see this athletic frame of mine slowly waste away. That is why the 'magents' (township lingo for guys) call this disease 'slow puncture' because it eats away very slowly at a person and end up humiliating you by making you lose all your bodily functions – ie. Soiling yourself, your mind going bananas, going blind, etc (Views of Tacash WCJ 14 CM).

### **Private versus Public Health Institutions**

This theme of private versus public health institutions such as government owned clinics and hospitals is also in agreement with what has been noted in the literature review as many respondents expressed a lack of confidence in the quality of services offered at government health facilities. Participants emphatically stated that they would cope with their HIV/AIDS positive status well by seeking treatment and care at private health facilities. The two interviewees, Mamokete and Tshepe, cited below summarize the views of most participants on this aspect this way:

Another important factor that causes stigma and discourages people from undergoing voluntary testing and counseling is the whole arrangement at government clinics and

other health facilities whereby there are dedicated queues for people collecting their antiretroviral medication – these queues are a total give-away that someone is HIV/AIDS positive - as well as entire sections dedicated to HIV/AIDS testing and to people who are HIV/AIDS infected. Now the public knows that if so and so lines up in that queue or entered ‘that’ section where voluntary counseling and testing are done and they take longer than usual to come out – then they know that there is a problem and that so and so must be delaying because of post-testing counseling usually given to people who tested positive (Views of Mamokete WCJ 05 CM).

Yet another participant expressed their views this way:

I would go to a private clinic because the service and confidentiality there is comparatively very good to that offered by government health facilities. I am still on medical aid insurance for over 25 years now and it is a health insurance scheme. You know it is good if you the infected person make a public disclosure about your positive status rather than the nurses and other health professionals employed at government clinics leaking your status to the public (Views of Tshepe WCJ 07 CM).

It would seem that a paradoxical irony is taking place here. Public health facilities are supposed to be the flagships in the fight against HIV/AIDS and its related primary and secondary stigma and yet they seem to be the main social structures perpetuating the stigmatization of the others.

As noted in the literature review section of this study, Gilbert and Walker (2009) explain that infected people observed in an HIV/AIDS clinic in Johannesburg showed that the fear of stigma and the related moral judgement, sometimes perpetuated by the medical personnel within the intimidating clinical setting, plays an important role in the patients’ reluctance to seek help in public health institutions.

Consequently, many people become also reluctant to undergo voluntary counseling and testing (VCT) as well as to receive HIV/AIDS treatment and care at public hospitals. This calls for the upgrading of professional standards at public hospitals as only good training concerning the ethical conduct of a public servant for the existing medical staff and the careful recruitment and selection of future personnel will help restore their seriously dented public image and reputation.

### **Medical Pluralism**

Medical pluralism is a theme is also in agreement with the literature the following are the interesting views expressed by one of the research participants and their views are interesting in as far as they show the openness of the society we live in as people can shop around for

treatment because of the wide 'hierarchy of medical resort' available offering many choices to individual healthseekers and their families in terms of treatment and care of their ailments. This contestation for space and influence between biomedicine and other alternative traditional forms of healing, is captured by Pontsho, one of the research participants, whose views are expressed below in this way:

Funny even though I come from a very strong Christian background I would seek help from the western medical professionals as well as use traditional herbs known to cleanse the body.

To me.....! I don't know but...but...but... I also believe that many of these western manufactured pills are compounds of natural herbs turned into pills. I would certainly give traditional medicine a chance even though at the moment I do not do any consultations with any Sangoma or fortune-teller and neither do my parents as far as I know. As a Christian I believe that herbs were also created by Our Lord to help us when we are sick or in need. Look how Jacob in the Bible out-manuevered his uncle by using a herb poured into the drinking water of his uncle's cattle to help them give birth to a particular breed of cattle that he made an agreement with his uncle to keep as his own reward for looking well after the cattle (Views of Pontsho WCJ 04 CM).

However, what is interesting is that culture and medicine are not mutually exclusive as traditional healers and biomedical healers are mutually consulted by African patients. Biomedical ideas of HIV/AIDS aetiology or sexual transmission are not just simply discarded but rather we see the fusion of western and traditional African medicine. African traditional medicine is personalistic and one of the crucial roles of personalistic medicine is to give an explanation as to why a specific illness has struck a specific person at a specific time. Personalistic medicine rationalises illness whereas western or biomedicine does not perform that important function. As Ashforth (2004: 151) states that:

Again we see a fusion of traditional and biomedicine, in that a man may acknowledge that he contracted HIV through sexual intercourse with an infected sex worker, and yet also seek the counsel of a traditional healer to discover who "sent" AIDS to him through witchcraft and why. Through this dual approach, people seek the answer to the question, "Why me?" Consulting the traditional and the biomedical healer makes many Africans feel that the treatment they receive is holistic and complete. Healing comes through music, drums, singing, herbal mixtures for consumption, enemas, scarification, and many other ways and thus harmony is re-established in society.

Williams (2003) and Scambler and Higgs (1999) explain that multicultural environments usually provide a myriad of alternative healing strategies but also highlight the fact that in homogeneous societies the understanding of health, illness and the resultant health seeking mannerisms can also differ in terms of age, gender and class. Ironically it would seem that the availability of alternative or pluralistic health seeking strategies is underpinned by tensions

that expose cultural contradictions that lead to inter-cultural clashes if not handled with caution and a more mature approach that views the differing healing paradigms as more being complimentary rather than being adversaries.

### **Medical Pluralism and Cultural Clash**

This theme on medical pluralism and the consequent cultural clash is in agreement with what has been noted in the literature review as many African people still cling to their cultural beliefs as well as making use of the benefits of western medicine. The confluence of the western urban culture and the indigenous traditional African culture does also create space for a cultural clash of some sort considering the fact that some of the residents in White City are migrants from the rural areas of South Africa. Now even though these rural areas have been tainted by western culture many of these areas still fall under the jurisdiction of traditional African Chiefs who are known to be custodians of African culture and actively promote the retention and practice of some customs and traditions. Therefore, when their subjects migrate into the city, they bring along their traditional belief systems and with a disease like HIV/AIDS it is very difficult to convince some of these traditional minded people as in African culture no disease is incurable. Firstly, incurability elicits arguments and suspicions about witchcraft and secondly incurability implies that the ancestors have a limited knowledge and power and therefore are unable to protect their descendants from hazards of some kind.

This is understandable considering the African perspective of personhood

Yes, maybe a significant majority but your ought to understand the population dynamics flow into and out of White City – people come from rural areas and neighbouring countries looking for brighter economic prospects in Johannesburg. Now because of the poverty levels in this township, some house owners allow these economic migrants to erect shacks at the back of their yards and stay in there for a monthly rental. Now you find that there is a confluence of the urbane and the rural traditional mentality with some of the urbane residents dismissive of traditional superstitions like witchcraft and on the other hand the rural folk suspicious of allopathic medicine. So there is a mix and clash of cultures in this equation and hence much more effort must be exerted in health education messages about the true nature of HIV/AIDS and how it can be acquired as well as defeated (Views of Masia WCJ 12 CM).

For biomedical researchers and epidemiologists, generally speaking, ‘culture’ appears to compromise intervention, whilst for medical anthropologists, ‘culture’ is often seen to have the potential to assist intervention.

Airhihenbuwa and Obregon (2000: 8) explain that:

In spite of its limitations, however, the use of opinion leaders in helping to shape culturally appropriate strategies is a component of diffusion of innovation that offers possibilities in HIV/AIDS communication. This is particularly salient since the content (focusing on a community interpretation of disease meaning rather than an imposed germ theory) context (relationships and negotiation in families and communities), and language (codes of elasticity of usage were relevant) of communication will be a factor in the outcome of HIV/AIDS prevention and care.

Generally speaking, a considerable number of Africans in the urban and rural areas are still very much steeped in their customs and traditions and therefore distrust the missionary health care workers as well as the western medical professionals. They prefer not to take western medicine and rely on traditional medicinal herbs as cures for their illnesses including HIV/AIDS. In other words distrust of western medicine and personnel coupled with alternative cultural beliefs also fuels the spread of this epidemic as many people who are unknowingly infected refuse to go to the clinics for voluntary HIV/AIDS testing.

The legacy of the apartheid system is such that many myths in the form of rumours spread unsubstantiated claims in the urban townships and in the countryside that, HIV/AIDS is a product of a biological warfare to reduce the numbers of Black people. Blame was apportioned to the American government/s and its network of CIA agents, as well as to Dr Wouter Basson, the former apartheid government's head of the secret 'biological warfare programme'. There is talk that some people even refused to buy oranges in the townships for fear that they may have been deliberately injected with the HI virus by agents of the apartheid government intent on annihilating the Black population which was by then in the 1980's fighting a war of resistance against apartheid.

## **5.2. CONCLUSION**

The various themes emerging from the fieldwork data analyzed seem to concur that the underlying cause for the HIV/AIDS prevalence levels as well as the associated primary and secondary stigmas come about as a result of structural issues which are responsible for creating an environment enabling the existence of a variety of multiple stigmas.

In the study of any type of stigma it is important to understand the socio-economic environment that makes it to thrive. It has since been established that stigma is not good and tends to have disruptive and harmful effects in society. First, the environment and conditions

that help to promote the sustenance of stigma need to be unmasked and understood so as to make it easier for the government and other stakeholders to develop programmes that will help towards alleviating stigma. Thus the context within which stigma operates is vital in helping to unmask reasons for stigma.

Secondly, it has also been established that secondary stigma is contingent upon the existence of primary stigma and therefore secondary stigma cannot be studied in pure isolation without mentioning and constantly referring back to primary stigma and the experiences of people enduring it.

Thirdly, the coping strategies employed by stigmatized individuals, families and other close associates are a good starting point to see what works and what does not work. Some of the coping strategies might actually be a form of self-stigmatization and hence it is important to establish a relationship between the socio-economic environmental contexts of stigma, reasons for the existence of stigma, the consequences of stigmas well as the coping strategies employed by individuals and families in order to survive.

## **CHAPTER 6**

### **CONCLUSIONS AND RECOMMENDATIONS**

In conclusion one would point out the fact that in the beginning this research report set out to investigate the dynamics of HIV/AIDS related secondary stigma in White City, Jabavu. However, it ended up going beyond the initial scope of its study because initially the project was fairly narrowly conceived but the findings from this research drove the researcher to explore, at some considerable length, two principal areas which were not part of the original conception of the project. These two areas are:

Firstly, the researcher's argument that stigma in White City must be understood in the broader context of pre-existing forms of stigma which he asserts create a "stigmatizing environment" in which new forms of stigma find a fertile social, cultural and economic world in which to take root and flourish.

Secondly, the researcher's recognition that the manner in which the research participants develop coping mechanisms to deal with their experiences of secondary stigma is a critically important dynamic in understanding the experiences of stigma among those research participants.

Therefore, as it stands, it is the humble opinion of the researcher that the Report goes beyond what might normally be expected of a Research Report, by moving beyond the concerns raised in the literature he worked with.

HIV/AIDS related stigma needs to be understood within the context of the pre-existing culture of stigmatization in White City. Chronic intergenerational poverty and unemployment are some of the plethora of underlying factors that create a multifactorial stigmatizing environment that eventually creates a culture of stigma in White City. Consequently, this is an important finding that sets the basis for future exploration by other researchers on this phenomena. Evidence of the pre-existing culture of stigmatization abound and can also be attested to by many examples as will be shown again below.

Firstly, linguistic structures of stigma such as assigning derogatory and discriminatory names like 'amakwerekwere' to fellow African economic immigrants and the name 'moegoe' to migrants from the rural areas of South Africa filtering into the township is a solid example of this pre-existing culture of stigma. As stated in chapter 1 the word 'moegoe' is a disparaging term meaning an unsophisticated country bumpkin or an unstreetwise hillbilly. Derogatory linguistic terms such as 'softy', 'sissie' or 'cheeseboy' abound especially in reference to young gentlemen who prefer communication to violence in settling interpersonal disputes.

Secondly, around Soweto schools, students from White City were always regarded with suspicion and when something went missing, they were always the first suspects.

Thirdly, as previously stated, in White City, a real man is a man who is not scared to engage in a street fight and if needs be to die fighting. Names such as 'clever', meaning a streetwise township guy, are not easy to earn and are some sort of a status symbol. The young men who steal vehicles and clone them are adoringly referred to as 'amagents' meaning that they are the right guys who are streetwise and proper to emulate. Failure to be like them means that you are automatically stigmatized because you are viewed as not being man enough.

Fourthly, the culture of stigma is also underlined by the kind of style and fashion one chooses to wear. Fashion denotes a type of lifestyle and membership of the 'Pantsula' fashion subculture assures one of a respectable social status by being favourably viewed as part of the real men who are tough and streetwise. On the other hand the 'Hippies' and the 'Ivy' fashion subcultures are looked down upon by many in White City as comprising of weaker men in many respects.

Furthermore, linguistic structures also include assigning discriminatory euphemisms such as '*U ne nculaza*', '*O na le Z3*' and others as discussed chapter 4 to refer to HIV/AIDS infected people.

HIV/AIDS and its related stigma do not enjoy precedence over pressing issues of poverty and unemployment whereby food security, shelter and other day to day material needs are a priority. In other words many young people in White City do not practice safer sex, not because they have not heard about it, but because poverty and the quest to survive drive them to engage in 'risky' behaviours. For instance the traditionally inferior position of a woman to that of a man further compromises women in terms of their bargaining power to negotiate safer sex using a condom. Many Black women are poor because they are unemployed and consequently succumb to the pressure of flesh-on-flesh sex without a condom for fear of angering a male partner who might retaliate by depriving them those gifts, money and other desirables necessary for daily survival. Therefore, the women of White City find themselves entrapped in this poverty cycle and consequently have to endure several layers of stigma such as being a woman, being black, unemployed, poor, HIV/AIDS positive, showing motherly love to their HIV/AIDS positive children and also for being White City residents.

## **Recommendations**

It is important to understand the socio-economic environment that makes secondary stigma and other kinds of stigma to thrive. It has been established that stigma is not good and tends to have disruptive and harmful effects in White City. The unmasking and understanding of the nature of the underlying factors that create layer of stigma upon layer of stigma will be a starting point for the government and other stakeholders to develop programmes that will help towards the systematic elimination of stigma. One of the ways to eliminate or minimize secondary stigma is to develop programmes targeted at addressing issues around HIV/AIDS primary stigma because without this kind of stigma secondary stigma which is fundamentally a stigma by association would not exist.

### **Joint special poverty alleviation and health promoting programmes**

A poverty stricken environment is a breeding ground of illness and disease. Therefore, both the government and the private sector would do well to join hands and initiate special skills programmes designed to empower the youth of White City by imparting valuable skills that would render them employable in the mainstream economy.

Morris (1980) observes that:

The relationship between socio-economic status and health in the community has certain implications:

- The overall improvement of the health status in Soweto can only be achieved through the upgrading of socio-economic and environmental conditions;
- a community based health programme integrated with a socio-economic development programme is required;
- while promotive and preventative medicine need to be emphasised, a range of services should be available;
- because of the high level of stress and insecurity in Soweto, both formal and informal services for mental illness are required;
- appropriate health education at all levels is a prerequisite.

Furthermore, various parastatals and Section 9 companies such as the 'National Development Agency' and the 'National Youth Development Agency (NYDA), to name but a few, should be encouraged to reserve a sizable portion of their annual budgets for the comparatively poor communities such as White City.

### **Good regulation of poverty relief grants**

Past and present structural issues play a role in perpetuating a stigmatizing environment in White City. The issue of poor substandard housing must be addressed by the government with the help of the residents of White City and other stake-holders. The current government's well intentioned grants meant to be a poverty relief mechanism for the indigents of the township must be carefully regulated to stop abuse and a culture of dependency. Instead alternative creative ways be sought that will help empower the local people, especially the youth.

### **Culture appropriate HIV/AIDS messages**

HIV/AIDS messages should be contextualized within local belief systems by being tailor made to suit the local culture because culture can play a crucial role in perpetuating or helping to alleviate primary and secondary stigma. The role of divergent local belief systems and cultural practices such as Christian religious values, African ancestral worship, circumcision and witchcraft must never be undermined and a holistic approach towards addressing issues around HIV/AIDS and its related stigma must be adopted as a vehicle to gain rapport amongst the people. Therefore, as a starting point one has to understand that the African perspective on the aetiology of HIV/AIDS differs from the Western biomedical idea of the 'germ theory' that explains that people get sick because of the germs and viruses that get into their bodies from the outside environment. The African perspective of HIV/AIDS transmission and symptomology is based on their cultural beliefs of pollution, ancestor intervention and sorcery which are deeply rooted and stigma arousing beliefs in these societies despite the extensive AIDS awareness and education campaigns in many parts of Southern Africa. Interesting in this discussion of African culture is the fact that HIV/AIDS infected and affected people have realized that by projecting the condition of the infected as the result of witchcraft, they manage to get expressions of sympathy from people not infected or affected by HIV/AIDS even though those sympathies come at a cost of social isolation as people keep away because no one wants their 'bad luck to rub on them.

### **Encouraging male circumcision**

Randomised clinical trials conducted in different Asian and African countries show that HIV/AIDS prevalence levels are lower among circumcised men than amongst those not circumcised. This seems to be a truism that has been proved by medical science and endorsed

by internationally renowned bodies such as the World Bank and the United Nations Organisation. This assertion does not discard the fact that HIV infection is basically caused by behaviour but tries to point out that a multifaceted approach that includes local and regional cultural beliefs must be employed together with the usual health education and health promotion campaigns geared towards eradicating the epidemic. In South Africa, studies done in Orange Farm, a relatively large and densely populated semi-urban settlement, show that circumcised males were less likely to be infected with the HI virus.

Szabo and Short (2000) in Wilson and de Beyer (2006: 3) explain that:

...circumcision removes Langerhans cells from the underside of the foreskin, which are specific target cells for the virus. It causes keratinisation (hardening) of the skin surface, and promotes more rapid drying which reduces the likelihood of bacterial sexual infections (like chancroid), which in turn reduces the risk of acquisition of HIV.

Taking into consideration the fact that circumcision is an ancient African tradition that is deeply rooted in culture, it would appear that many African men find this practise acceptable culturally and politically correct as it asserts their manhood. Men are said to cheat a lot and maintain multiple concurrent sexual relationships with a number of female sexual partners. This scenario puts an emphasis on the traditional definition of male masculinity as well as on the male versus female power relations, with the male being assigned a socially superior status to that of a woman. Therefore, as a prevention tool against HIV/AIDS that has been proven to work, it would be a wise move by the South African government to encourage male South Africans to circumcise in addition to employing other known prevention methods such as condom use, abstinence and being faithful to their partners.

### **Appropriate messages complimenting popular coping strategies**

Coping strategies employed by people enduring secondary stigma are many and are meant as an escape route vacillating between the emotional and psychological strategies such as turning to religion, rationalisation, denial, disclosure, non-disclosure, going for counselling, acquiring knowledge about HIV/AIDS, fatalism and suicidal tendencies, changing lifestyle and so on. These coping strategies are a good starting point to see what works and what does not work in terms of offering support to the victims of stigma. Some of the coping strategies such as fatalism and suicidal tendencies are actually a result of self-stigmatisation, self-hatred and self-mutilation and hence it is important to establish a relationship between the

stigmatizing context, the reasons for stigma, consequences of stigma and the coping strategies employed by individuals in order to cope with their hostile environment.

Finally, it is proper to acknowledge that the research findings point strongly to the existence of secondary stigma in White City, Jabavu but what is also of crucial importance is the research finding and realization that this secondary stigma exists within an environment of an already pre-existing age-old culture of stigmatization.

### **Redressing negative historical factors**

Unearthing secondary stigma is a complex process that needs people to come to terms with the underlying historical factors such as the impact of colonialism, the effects of the processes of industrialization and urbanization, that helped to disintegrate the African extended family as a result of the migrant labour system as well as contemporary post-apartheid socio-economic policies and other factors that play an important role in exacerbating inequality and thus creating a stigmatizing environment in places such as White City Jabavu, Soweto.

Like in most Black urban areas as well as in the Black rural countryside, poverty and the resultant social inequalities in White City are a legacy of the past racial policies that put people in harm's way. The apartheid system that was based on racial discrimination and segregation had sought to relegate Africans, especially Blacks, to an inferior third class citizenship status in South Africa. Poverty and the resultant social inequalities create ideal conditions for socially abhorrent practices such as multiple concurrent sexual partnerships (MCSP), alcoholism and drug abuse, potentially unhygienic and life threatening sexual practices such as dry sex, crime and gangsterism, lack of good nutrition, gender abuse and other social maladies that are thriving in the Black communities.

Goffman (1963) was probably right when he stated that the act of stigmatizing the others is an attempt to reassure oneself that one is still normal. Therefore in consideration of the history of Black people's oppression in South Africa, it is not far-fetched to state that primary and secondary stigmas are mostly acute in the most impoverished Black communities such as White City as unstigmatized people try to reaffirm their normalcy, dignity, masculinity and humanity at the expense of the more vulnerable others who are inclined to be made scapegoats because they are HIV/AIDS infected or affected.

Stigma affects the social identity of an individual and those people stigmatized are characterized by a very low self-esteem, feelings of inferiority and a feeling of being less human than other people meaning that their normalcy is in dispute.

Nevertheless, even though there is no evidence to suggest a strong causal relationship between HIV/AIDS and poverty, it is only sensible to realize that malnutrition and a lack of financial resources can only play a bigger role in further compromising the already weakened immune system of the infected person as good treatment and care are contingent upon the availability of financial resources and a healthy diet.

### **Improving the socio-economic position of the Black woman**

On the other hand in terms of gender relations, African (Black) women are exposed to multiple stigmas, firstly because of their black pigmentation, secondly, because they are culturally and traditionally regarded as inferior to their men-folk and then thirdly because many are less educated, poor and unemployed as compared to their men-folk. Their decision making powers are curtailed because in terms of their sexuality they have no absolute control over their bodies. They cannot negotiate safer sex because decisions such as the usage of a condom to practice safer sex are left to the man for fear of suffering financial sanctions if they refuse to let him have his way.

At the level of the average African family in White City the scarcity of financial resources is the cause of much primary stigma that is inflicted by family members upon one of their own who is infected because they view him or her as an unnecessary burden straining the already meager family resources. Most women are the caregivers and therefore suffer a multiplicity of stigmas as a result of: firstly, living in White City, secondly, for being poverty stricken and thirdly, for being associated with a sick member who is HIV/AIDS positive. It is noteworthy to highlight the fact that even one's extended family members who live in the more affluent townships of Soweto normally look down upon their brethren who live in White City and the stigma becomes even more intense when such a family has a member who is HIV/AIDS afflicted.

It would seem that secondary stigma is experienced intensely as the health of the afflicted member of the family deteriorates. Curious community members engage in gossip and voyeurism as they use benchmarks such as the dramatic loss of weight, the development of Kaposi's sarcoma, skin rashes, constant diarrhea and other negative health conditions. The

irony is that these community members are the ones who initially isolated and rejected the family but later on become regular visitors as they engage in gossip and voyeurism. In a subtle manner they check on the pace of the physical deterioration of the infected person so as to keep the others in the community informed. This creates a vicious cycle of stigma and self-stigmatization as the social esteem of the infected individual and his or her family goes down resulting in social withdrawal and isolation that creates a wall between that family and the community at large. Self-stigmatization is a consequence of felt or perceived and enacted stigma and is tantamount to an act of self-mutilation which is an unfavourable psychological condition that needs intense therapy. It is thus again to re-emphasize the fact that because most caregivers are women, they endure a lot of this secondary stigma and therefore official programmatic efforts to improve the economic position of poor black women in White city, as well as in the rest of the country must be accelerated. It is not enough to salute women only on a public holiday like the 09<sup>th</sup> August each year and yet women still remain impoverished and victimized.

As a result it is important to note that this study highlights the fact that secondary stigma exists within a pre-existing culture of stigma in White City, Jabavu.

Thus, the combination of all these past and current socio-economic factors put White City at a centre stage of post-apartheid social inequality with a barrage of underlying factors that perpetuate the culture of stigma by acting in unison to facilitate the prevalence of secondary stigma.

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## APPENDIX A

### **IN-DEPTH INTERVIEW GUIDE**

[Researcher: Caswell Motlejoa Matima-University of the Witwatersrand]

- 1) Could you please tell me more about yourself- i.e. where you grew up, your childhood years, how you related to your family, friends, neighbours and so on
- 2) What are the socio-economic conditions of White City?
- 3) How do people spend their leisure time in White City?
- 4) What are your views on HIV/AIDS and people infected HIV/AIDS?
- 5) What is the understanding of HIV/AIDS in White City?
- 6) What is the attitude of ordinary people towards HIV/AIDS?
- 7) What are the views of ordinary people about other people infected and affected by HIV/AIDS?
- 8) Do you understand how HIV/AIDS is transmitted from one person to another?
- 9) Should you find out that you are HIV positive-what would you do?
- 10) Should you find out that you are HIV/AIDS positive how do you expect other members of society, not closely related to you, to treat you?
- 11) What makes HIV/AIDS to be a stigmatized disease?
- 12) What is the understanding of stigma amongst the people of White City?
- 13) What are the experiences of secondary stigma amongst people affected by HIV/AIDS?
- 14) What is the impact of secondary stigma in the community?
- 15) How does secondary stigma impact on people closely associated with an infected person?
- 16) What are the coping strategies of people affected by HIV/AIDS?
- 17) Do they get any kind of support from anywhere?
- 18) What role can the government and other stakeholders better serve people affected and infected by HIV/AIDS?

## APPENDIX B

### CONSENT FORM - INDEPTH INTERVIEWS

I, .....,hereby agree to be interviewed by Mr Caswell Motlejoa Matima, student ID No: 418051, who is a registered student at the University of the Witwatersrand and currently engaged in his Masters Research Report on Secondary Stigma related to HIV/AIDS entitled:

“Secondary Stigma: A Case Study of People Affected by HIV/AIDS in White City, Jabavu – Soweto.”

Mr Matima has explained to me the entire research process and the fact that I am free to terminate/recuse myself from the interview as soon as I find it too invasive and uncomfortable to continue. Furthermore, Mr Matima has explained to me and also gave me an assurance that my true identity will remain highly confidential due to the sensitive nature of this topic. I agree to voluntarily partake in this in-depth interview and hope that my experiences and views will be useful in building more knowledge in this area of research.

---

Name

---

Signature

---

Date

## APPENDIX C

### DIGITAL RECORDING CONSENT FORM

(Secondary stigma: A case study of people affected by HIV/AIDS in White City, Jabavu – Soweto)

I....., hereby give permission to Mr Caswell Matima (a Wits University research student) to use a digital recorder or any kind of an audio-recorder to capture our conversation during our in-depth interview session.

I also give permission to Mr C.M. Matima to write down ALL the opinions, experiences, comments and answers by me in addition to his usage of an audio-recorder.

This is a voluntary decision taken by me as an individual after getting a full explanation about the real purpose/s of this study. Mr Matima promised to keep my real identity very confidential by using a pseudonym at all times when taking notes and when writing his final research report to protect me from any unforeseen harmful effects during and after the course of his study.

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Name

---

Date

---

Signature

## APPENDIX D

### LIST OF COUNSELLING RESOURCES

I am acutely aware of the fact that any personal discussion on HIV/AIDS touches on deeply intimate dimensions of our lives. For some, such discussions may touch on painful and traumatic experiences in the past or painful and traumatic experiences in the present and this may result in some people feeling upset or distressed.

While every effort will be made by the researcher to be sensitive to this possibility with all research participants, sometimes he may well not be aware of your discomfort. So, if the discussion in the interview session/s have raised issues in your life that you feel you need to follow up on, to talk to someone about or to receive counselling of some kind, here are some suggestions that you would be encouraged to pursue:

Indicate your discomfort to the interviewer.

Indicate whether you would like to continue with the interview or not or that you merely need a temporary break to help recover your composure.

Speak to a person in a position of leadership whom you respect in your family or religious organisation **OR** contact one of the organisations listed below:

Lifeline (a phone counselling service) 011 728-1347

Family Life Centres (Comprehensive Counselling):

Johannesburg City Centre 011 833-2359

Soweto 011 986-3290

POWA (People Opposing Women Abuse) 011 642-4345

NICRO (Work with victims of crime and abuse)

Johannesburg 011 403-8166

Soweto 011 986-1020

CSRV Trauma Clinic (Braamfontein) 011 403-5102

Your local clinic

**APPENDIX E**  
**PARTICIPANTS INFORMATION SHEET**

**(C.M. MATIMA- MA FIELD RESEARCH)**

AGE	GENDER	OCCUPATION	PSEUDONYM
29 years	Male	Security Guard	Sporo
34 years	Female	Manager	Mantsopa
40 years	Male	Sales Representative	Dayoff
47 years	Male	General Assistant	Mphatlalatsane
47 years	Female	Librarian	Elisabetha
50 years	Female	Teacher	Pontsho
53 years	Female	Garment Factory Worker	Tatibi
54 years	Male	Medical Doctor	Masia
54 years	Female	Nurse	Mamokete
54 years	Male	Priest	Sekhothu
56 years	Female	Lay Health Worker	Maria
58 years	Male	Debt Collector	Tacash
59 years	Male	Motor mechanic	Lehlohonolo
61 years	Male	Administrator	Tshepe
68 years	Female	Traditional healer	Tau ea Matshekha

(Secondary Stigma: White City, Jabavu – Soweto)